

**Depression, self-perception and emotional understanding
in children and adolescents with Asperger syndrome**

&

Research Portfolio

**PART ONE
(Part two bound separately)**

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123 21

Table of Contents

Part one (this bound copy)

| | Pages |
|--|---------|
| Chapter 1 Small Scale Service Evaluation | |
| An evaluation of the introduction of an ‘initial assessment’ model of service delivery in a clinical psychology service. | 1-26 |
| Chapter 2 Literature Review | |
| Emotional understanding, self-perceptions and depression in high-functioning individuals with an autistic spectrum disorder. | 27-54 |
| Chapter 3 Proposal for Major Research Paper | |
| The relationship between perceived self-competence, emotional understanding and depression in high-functioning children with autism. | 55-75 |
| Chapter 4 Major Research Paper | |
| Depression, self-perception and emotional understanding in children and adolescents with Asperger syndrome. | 76-110 |
| Chapter 5 Abstract for Clinical Research Case Study | |
| Evaluating Narrative Therapy: A process and outcome study. | 111-112 |



Table of Contents (cont.)

Part one (this bound copy)

| | Pages |
|---|---------|
| Chapter 6 Appendices | |
| Section 1: Appendices for Small Scale Service Evaluation | 114-118 |
| Section 2: Appendices for Literature Review | 119-120 |
| Section 3: Appendices for Major Research Proposal | 121-139 |
| Section 4: Appendices for Major Research Paper | 140-141 |
| (Appendices for Clinical Research Case Study bound separately in part two) | |

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This research portfolio is dedicated to my mother.
Thank you for everything, and for giving me wings.

CHAPTER 1: SMALL SCALE SERVICE EVALUATION

**An evaluation of the introduction of an ‘initial assessment’ model
of service delivery in a clinical psychology service.**

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**Prepared in accordance with guidelines for contributors to Health Bulletin
(Appendix 1.1)**

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ABSTRACT

Objective: To evaluate the introduction of an initial assessment model of service delivery within an adult clinical psychology service.

Design: The evaluation period was 6 months. Three self-report questionnaires were designed to assess patient, psychologist and GP satisfaction with this service. Patients and GPs received these by means of a postal survey with the psychologist completing a questionnaire following the assessment of each patient. The number of patients waiting for treatment, records of attendance, waiting time for initial appointments and referral rates were analysed so that implications for service delivery could be investigated.

Setting: East Renfrewshire, Scotland.

Subjects: Respondent patients (n=30), General Practitioners (GPs) who referred to the service during this time (n=14) and one full-time Clinical Psychologist.

Results: Questionnaire responses revealed high levels of satisfaction with this model of service delivery, although, patients, GPs and the Psychologist frequently reported dissatisfaction with waiting time for treatment appointments. The GPs reported that the service was preferable to the previous waiting list system, highlighting a number of strengths that may encourage them to refer more patients. In comparison to the period 6 months prior to implementation of the initial assessment model, average waiting time for first appointments decreased by 75%, non-attendance at initial appointments decreased by 85%, and monthly referral rates increased by 38%.

Conclusions: The introduction of an initial assessment clinical psychology service has revealed a number of benefits for consumers, purchasers and providers. The results suggest that waiting time is a critical factor affecting satisfaction and demand and, once again, has stressed the need for adequate resourcing of clinical psychology services.

INTRODUCTION

Long waiting lists for clinical psychology services are a national problem (Stevenson et al., 1997). A survey carried out by the British Psychological Society Division of Clinical Psychology (1993) showed that 44% of people referred to responding clinical psychology departments waited over six months to be seen, whilst 15% waited over 12 months. These figures were far removed from the 13 weeks waiting time standard proposed in the Patients' Charter (April, 1997). McAuliffe and MacLachlan (1992) reported findings of their survey of Greater Glasgow Health Boards Mental Health Unit, which showed that patients and GPs most frequently reported long waiting time to see a clinical psychologist as a sign of a poor service.

More recently several alternative methods for managing this problem have been proposed (Newnes, 1993; see Startup, 1994), the consensus prevailing being that different ways of working will be necessary (Crawford, 1988; Newnes, 1988; Robertshaw and Sheldon, 1992). However, there is little agreement as to what constitutes the most satisfactory or efficient way of working. Information provided by the McAuliffe and MacLachlan (1992) study revealed that patients and GPs remain in favour of a system where everyone referred to a clinical psychologist, is offered an assessment appointment prior to being placed on a waiting list. Geekie (1995) evaluated this approach and reported a number of benefits, including: quick identification of the nature and urgency of presenting problems; quick referral of inappropriate referrals to other agencies; and the provision of early advice for appropriately referred patients until treatment commenced (Blakey et al., 1995).

This study investigates initial levels of satisfaction and some of the clinical practicalities and benefits experienced by those involved in an initial assessment system. A number of studies

have utilised either patient satisfaction (Blakey et al., 1994; Shawe-Taylor et al., 1994) or GP satisfaction (Griffiths & Cormack, 1993; Seager et al., 1995) to evaluate a clinical psychology service, however, few have done both (McAuliffe & MacLachlan, 1992). Far less have formally assessed psychologist satisfaction with service delivery, relying on rather anecdotal reports and perceptions post-evaluation (Brownescombe-Heller, 1996; White, 1998). Geekie (1995) relied on informal discussions with patients and GPs and clinical impression to evaluate satisfaction with assessment appointments prior to waiting. This project aims to evaluate formally satisfaction with service delivery from each perspective (patient, psychologist and GP), reflecting the belief that the three opinions are of equal importance and are necessary together to provide a comprehensive picture of service satisfaction.

Background

The project was conducted within an Adult Mental Health Clinical Psychology Service in East Renfrewshire. Greater Glasgow Community and Mental Health Services NHS Trust (GGCMHT) took over the administration of services in this area on the 1st April, 1998. This represented one of the largest contracts won by a trust in the UK. One reason for GGCMHT's success was the undertaking given by the trust that waiting time for psychological services would be reduced to a maximum 12 week period. This commitment had been realised by August 1998 and remained stable in the months prior to this evaluation. The system in place at this time involved a twelve week waiting period prior to first contact and treatment. In an attempt to try to maintain a low waiting time, a further waiting list initiative was introduced, involving initial assessment appointments prior to waiting.

In January 1999, GPs were informed by the Clinical Psychologist that, forthwith, referrals would be seen via an initial assessment system, with this approach involving the offer of a one-off assessment appointment with a Clinical Psychologist, utilising a semi-structured assessment interview and formal psychometric measures, including the Beck Depression Inventory – II, the Beck Anxiety Inventory and the CORE Outcome Scale (34-item version). The appointment, to last for one hour, would provide, at its conclusion, agreement between patient and psychologist as to which form of treatment would prove to be most beneficial. Amongst a number of possible conclusions of the assessment appointment, there would be included the receiving of: a place on the waiting list for further therapy from clinical psychology; referral to another service or to a group treatment format; self-help material; or no further treatment. No one of these were exclusive but, whatever the outcome, both the GP and the patient would receive typed feedback from the assessment interview, summarising the presenting problem and formulation, scores on the measures administered and resulting recommendations. In February 1999, the first such assessments took place. This study has evaluated some of the implications of this models implementation, within this service. The specific aims of the evaluation were:

- To assess patient satisfaction with a one-off assessment appointment prior to being placed on a waiting list.
- To assess clinical psychologist's satisfaction with, and confidence in this model.
- To gather GP opinion of the initial assessment model of service delivery, as compared to the previous waiting list system.
- ♦ To investigate any implications for service delivery/management.

METHOD

Design

The study was designed to evaluate the implications of a new model of service delivery for an adult mental health psychology service. The evaluation period took place over a 6 month period, commencing in February 1999, when the first assessments took place, with data collection being completed at the end of July 1999. The participants comprised patients seen during the specified time (n=53), the psychologist who carried out the assessments (n=1), and GPs who had referred to the service during this time (n=22).

Measures

Three questionnaires were designed to survey respectively, patient, psychologist and GP satisfaction with this model of service delivery (see Appendix 1.2 for a copy of the questionnaire measures). In addition, service delivery statistics during the 6 month period were collated and compared with statistics from the previous 6 months, to evaluate any implications for service delivery.

Questionnaires

The questionnaires were designed specifically for this study as, at the time, no existing standardised measures were appropriate. They were developed in consultation with the psychologist involved, whilst acknowledging methodological issues involved in the use of questionnaire measures. The questionnaires will be described individually below and are presented in Appendix 1.2.

Patient Satisfaction Questionnaire

This consisted of seven questions designed to assess satisfaction with the specific attributes of this model of service delivery, namely: waiting time for assessment, and for treatment, the process and content of the assessment interview, utility of self-help material, and confidence that future clinical psychology intervention would be helpful. All questions were forced choice, utilising both 5-point likert-type scales and "yes" and "no" response categories. The scales were rotated intermittently to reduce the likelihood of response anchoring. The questionnaires were sent to each of 53 patients involved in the rapid assessment process, over the specified period, together with a stamped addressed envelope for ease of return. A covering letter was included also, which confirmed the confidentiality of each patient's anonymous response and responses would not affect, in any way, the service which each received.

A postal survey conducted by a person, impartial and independent of the service, has been suggested as one way of reducing the influence of social desirability on responding (Skaiffe & Spall, 1995). This design was selected, acknowledging the possibility of a low return rate, commonly reported to be between 30 and 40% (Skaiffe & Spall, 1995; Stallard & Chadwick, 1991). Patients received the questionnaires, on average 5 weeks following the initial assessment appointment (range 1-9 weeks), to produce variability in time waiting and thus, in responding. Four batches of questionnaires were sent. The timing of forwarding each questionnaire was also given careful consideration for, had patients received them immediately following the assessment, they would not have experienced the implications of the model fully, particularly the waiting time aspect. It also may have increased the influence of social desirability on responding (Stallard & Chadwick, 1991), and, thus, a variable waiting time was utilised.

Psychologist Satisfaction Questionnaire

This was designed to be quick and easy to complete, and to cover the main aspects of the assessment interview, together with its implications. It consisted of 4 questions designed to assess satisfaction with the time allocated for assessment; the time that each patient would wait for treatment; understanding of the patient's problem; and perceived utility of the assessment interview for the patient. All questions were forced choice, utilising both 5 point likert-type scales and "yes" and "no" response categories. The scales were not rotated to assist ease of responding. The questionnaires were completed by the psychologist, following each assessment interview (n=53), conducted in the specified timescale.

GP Satisfaction Questionnaire

This consisted of seven questions which attempted to assess the following areas: whether the GPs thought that the initial assessment system provided a better service for them and for their patients, as compared to the previous waiting list system; what aspects they saw as the strengths and weaknesses of this model; whether they would refer more patients to a service offering an initial assessment; and whether the feedback given after assessment provided the appropriate amount and type of information. The questions asked for a "yes" or "no" response, and invited further comment. The questionnaire covered one side of A4 only, to increase the likelihood of completion (White, 1998). Blakey (1996) discusses the merits of face-to-face communication with GPs, prior to requesting that they complete questionnaires, however, this was not possible in this instance. Instead practice managers were willing to assume responsibility for distribution and return of completed questionnaires, using the stamped addressed envelopes provided. GPs received the questionnaires at the end of the sixth month evaluation period, but only those who

had used the initial assessment system, and the previous system were invited to respond (thus excluding locum GPs), as the questions required an appropriate comparison (n=22).

Service Delivery Statistics

Records over the six month evaluation period of the outcome of assessment appointments, waiting time for initial appointments, attendance at initial appointments and GP referral rates were maintained, in order to monitor the implications for resources and service delivery. The latter three data sets were compared to records from the six months preceding, prior to the introduction of the initiative.

RESULTS

The results will be described in four parts, in line with the areas under evaluation.

Questionnaires

The questionnaires were analysed in the following manner. Every question on each of the questionnaires was considered separately, and the number responding to the respective categories for that question was totalled. In relation to open-ended questions detailed in the GP questionnaire, responses were categorised post-completion, and the number endorsing each response was recorded. Description will relate to the pattern of results; percentages and raw scores are shown in the relevant Tables.

Patient Satisfaction Questionnaire (see Table 1)

Thirty one patients returned their questionnaires, producing a response rate of 58%. The majority of patients reported being satisfied with the time that they had waited for their first

appointment. Approximately the same number of patients reported satisfaction, as reported dissatisfaction, with the waiting time for their treatment appointment. The majority reported satisfaction with the duration of the initial appointment, the remainder suggesting that more time would have been preferable. Most were content that, that the psychologist had understood the nature of their problems, with only a minority reportedly feeling unhappy with this aspect of the assessment interview. The type of advice/treatment offered was reported as adequate by most, with a small number only dissenting from that view. Those who received self-help information, reported it as helpful. Most respondents reported their confidence that the clinical psychology service would prove able to be of assistance to them.

INSERT TABLE 1 ABOUT HERE

Psychologist Satisfaction Questionnaire (see Table 2)

Fifty three questionnaires were completed, representing a 100% response rate. The amount of time allowed for assessment of each patient, was reported to be adequate, for the majority of the appointments. For the remainder, an additional 15 or 30 minutes would have been preferable. The Clinical Psychologist reported being satisfied she had gained an adequate understanding of the patient's problems, for most of the assessments. On each occasion that dissatisfaction with understanding of the problem was reported, additional time was also suggested as desirable. The Psychologist reported being satisfied that the initial assessment had proved beneficial for most patients, but reported being unhappy that the patient would wait for treatment for approximately one half to one third of those assessed.

INSERT TABLE 2 ABOUT HERE

General Practitioner Satisfaction Questionnaire (see Table 3)

Fourteen GPs returned the questionnaires, producing a response rate of 64%. Those who responded reported that this service was preferable to the waiting list system previously adopted. The strengths of the initial assessment system, as suggested by respondents, can be grouped into categories, which include the ability to screen, prioritise and triage, build confidence in the service, and to provide early therapeutic contact and benefit.

INSERT TABLE 3 ABOUT HERE

Approximately 50% of the GPs suggested that no weaknesses were apparent with this model of service delivery, but those that were narrated can be grouped conveniently, by identifying the following themes. These included the possibility of lengthy waiting times for treatment appointments, raising patients’ expectations, increased referral rate, and using less of the psychologist’s time. Each GP reported that this approach provided a better overall service for their patients, the majority suggesting that they would be more likely to refer to a service offering an initial assessment appointment. Their reasons for referring more patients can also be grouped and include, being able to refer those who would possibly benefit from psychological treatment utilising the screening system and early professional opinion, refer more patients for crisis management, for the therapeutic benefit of the consultation, and because previously the waiting time had often proved to be unhelpful for the patient. Those who commented, reported finding that the amount and type of information provided on the assessment forms was adequate and appropriate.

Service Delivery Statistics

28% of the patient sample was not returned to the waiting list. 9% were offered immediate treatment, either because their problems were assessed as urgent, or because court reports had been requested. 13% required no further treatment following the consultation, and 6% were referred either to a group treatment format or a CPN service (see Table 4).

INSERT TABLE 4 ABOUT HERE

The time spent awaiting an initial appointment in the previous 6 months averaged 12 weeks. For those involved in the rapid assessment system, the average waiting time for initial appointments amounted to 3.8 weeks, with a range of 2-6 weeks, and represents a 68% reduction in waiting time. Attendance at initial appointments was improved significantly with only 2 patients failing to attend their first appointments, during the 6 month evaluation period, as compared to 13 in the 6 months preceding (see Table 5 and Figure 1). This comparison represents a decrease in non-attendance of 85%. The average referral rate increased by 38% during the 6 months of the initial assessment service.

INSERT FIGURE 1 AND TABLE 5 ABOUT HERE

DISCUSSION

The results demonstrate high levels of satisfaction as attested to by the patients, GPs and Clinical Psychologist involved in the initial six months during which the rapid assessment system was initiated. Associated records of service delivery have highlighted several important implications of this model in relation to a Clinical Psychology Service.

The majority of patients reported satisfaction both with the time waiting for the initial assessment and, with the content of this assessment. However, patients remained less satisfied with the length of time they might have had to wait for treatment, although it should be remembered that they would not have known how long this period might prove to be. This result could be assessed for a greater degree of validity, therefore, at the time of treatment appointment. The majority of patients confirmed that the clinical psychology service would be of assistance. Shawe-Taylor et al. (1994) reported similar results of increased patient confidence in the degree of assistance, which could be gained from a Clinical Psychologist, following an initial assessment.

Several of the responses provided by the psychologist questionnaire, suggested that an extra 15-30 minutes of appointment time would have proved more satisfactory for almost half of the sample. This is particularly relevant when the information gathered within this time frame, determines decisions regarding treatment. Generally, patients did not report a similar level of dissatisfaction, but this difference may have reflected a greater experience of brief clinical appointments. For thirty nine percent of those patients awaiting treatment, the psychologist reported feeling quite unhappy about this. Again, this reflects a high level of dissatisfaction with the lengthy waiting time for treatment appointments engendered in this model of service delivery. The psychologist generally reported that the appointment had been beneficial for the patient, a view point underlined by the GP responses supporting a therapeutic benefit, from assessment appointment.

The GP's responses confirmed that this approach was preferable both for them and for their patients, to the previous treatment waiting list system, thus lending additional credence to the results provided by McAuliffe & MacLachlan (1992). The small sample size may have produced a response bias, although opinion was almost unanimous. They accentuated a number of benefits highlighted by the model, including rapid contact with psychology services and the availability of a screening, prioritising and triaging service. These benefits have also been reported in previous research (Blakey et al., 1995; Brownescombe-Heller, 1996; Geekie, 1995). The majority of GPs reported that they could see no weaknesses with the application of this model, a considerable proportion suggesting that the benefits implicit in the provision of an initial assessment service would encourage them to refer more patients in this direction.

Service delivery statistics demonstrated an increase in referral rates, consistent with the GPs suggestions. This may reflect a trend in increased referral rate over the twelve month period (see Figure 1), however, there are reasons for believing such an increase may result from the implementation of this service. Previous research has suggested that GPs limit their referrals to Clinical Psychology, when a lengthy waiting list exists (Startup, 1994), additionally, an increased referral rate being reported by Partridge et al. (1995) when a similar model was implemented. Taken in conjunction with the GPs responses, the results support the suggestion that referrals to Clinical Psychology services had been limited by waiting time. With the initial removal of this barrier, a more accurate reflection of demand for Clinical Psychology services had been realised. Without a parallel increase in clinical psychologist time, this increase has the potential to highlight the weaknesses of the model.

Is this model in this setting, the answer to the waiting list problem? There is no longer a waiting list for Clinical Psychology assessment but, the same observation can not be made for treatment. Robertshaw & Sheldon (1992) reported that poor implementation of this model could result in simply replacing one waiting list with another. Their findings have not been supported by the results of this project, because the new waiting list group is both quantitatively and qualitatively different from the first. Firstly, a number of patients were not referred for treatment and accordingly this has reduced the size of the waiting list. Secondly, those who were waiting for treatment had been assessed as potentially benefiting from clinical psychology intervention, and had not been found to require treatment urgently. They also had knowledge of what treatment may involve with a majority receiving self-help information. The model appears to reflect a more efficient and satisfactory method of managing a waiting list.

The dramatic reduction in non-attendance at initial appointments is further evidence to substantiate the increased levels of efficiency inherent in this model. This might be explained by the reduction in waiting time (McGlade et al., 1988), although an alternative aspect of the model which may have influenced the reduction is the one off nature of the appointments. This may reduce anxiety with regard to the appointment, and may encourage those who are ambivalent about treatment to come along, in order to state that this is so, rather than remaining on a waiting list and, ultimately, ignoring the appointment. The reduction in non-attendance is greater than that reported by "opt-in" waiting list initiatives (Markman & Beeney, 1991; Waring et al., 1999) and would merit further research.

Clearly, there are considerable benefits from this system, but what of its related weaknesses which, during the first six months, may be viewed as hypothetical in nature only? The study of

waiting time for treatment remained beyond the scope of this project but it does appear to play a central role in creating satisfaction. The patient, psychologist and GP responses report consistent dissatisfaction with the length of waiting times for treatment. Therefore, it is recommended that the above measures are repeated in six months, to determine actual waiting time, and to evaluate related levels of satisfaction. However, one reason for suspecting that waiting time for treatment may become lengthy is the level of increase in GP referral rate. If the rapid assessment system continues, and the level of referral rate continues to increase, the Clinical Psychologist may be forced to spend more time on assessment, and correspondingly less on treatment. The patients who did not require further treatment, or who were referred for group treatment formats are (from the results of this research) too few in number to affect this problem significantly. A number of options could be instrumental in reducing this problem, including: increasing the threshold level for deciding that a patient requires one-to-one psychological treatment, increasing the availability of group treatment formats, training other professionals to carry out psychological interventions and providing more clinical psychology time.

Future research could assist in clarifying concerns that these results may be temporary and/or service specific. An evaluation of this model over the next six months could help to clarify the first point. An evaluation of the introduction of this model of service delivery, within another service, could help to determine the second, whether these results reflect satisfaction with this model, or satisfaction with this Clinical Psychology service.

CONCLUSIONS

This research concludes that the initial assessment approach to service delivery, for those involved in this project, has produced high levels of satisfaction both for consumer and provider, with purchasers having found this approach to be preferable to the previous waiting list system. However, the concern is that this may be time-limited, falling prey to the dissatisfaction of long waiting times, as demand for the service increases. Ultimately perhaps, the difficulties experienced as a result of lengthy waiting time can be tackled effectively only by purchasing Clinical Psychology resources sufficient to meet demand and sustain levels of satisfaction with service delivery.

Assessing satisfaction with this model of service delivery from three distinct perspectives has proven to be extremely productive, perhaps providing a more comprehensive illustration of its implications. Consumers, purchasers and providers could be said to be reviewing quite different experiences of the initial assessment model, yet have come to similar conclusions regarding the strengths and shortcomings of the model. There are obvious limitations in the utility of deciding service delivery policy from a single perspective alone and so evaluation of levels of satisfaction obtained from each of the three perspectives could form a necessary part of a full evaluation of service delivery.

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LIST OF FIGURES

| | Page |
|---|------|
| Table 1: Percentage scores on the Patient Satisfaction Questionnaire | 22 |
| Table 2: Percentage scores on the Psychologist Satisfaction Questionnaire | 23 |
| Table 3: Percentage scores on the GP Satisfaction Questionnaire | 24 |
| Table 4: Percentage and raw scores of patients receiving each outcome of assessment appointments | 25 |
| Table 5: Records of service delivery statistics 6 months prior to the initial assessment and during the first six months of the initial assessment period | 25 |
| Figure 1: GP referral rate 6 months prior to the initial assessment and during the first 6 months of the initial assessment period | 26 |

Table 1: Percentage scores on the Patient Satisfaction Questionnaire

| Questions | Response Type (%) Sample Size 100% (n=31) | | | | | | |
|---|--|--------------------|------------------------------------|--------------|-----------------|----------------|---------|
| | very dissatisfied | quite dissatisfied | neither satisfied nor dissatisfied | | quite satisfied | very satisfied | |
| How satisfied are you with the time you had to wait for your first appointment? | 0% | 0% | 6% | | 43% | 51% | |
| How satisfied are you with the time you will wait until your second appointment? | 22.5% | 16% | 23% | | 16% | 22.5% | |
| How satisfied are you that the psychologist understood the nature of your problems? | 0% | 16% | 6% | | 23% | 55% | |
| How satisfied are you with the type of advice/treatment you have been offered? | 3% | 13% | 16% | | 26% | 42% | |
| Questions | Response Type (%) Sample Size 100% (n=31) | | | | | | |
| | YES | | NO | | | | |
| Were you satisfied with the duration of the appointment? | 90% | | 10% | | | | |
| If no, would you have preferred? | | | 1 hr more | 30 mins more | 15 mins less | 15 mins | 30 mins |
| | | | 0% | 7% | 3% | 0% | 0% |
| Questions | Response Type (%) Sample Size 74% (n=23) | | | | | | |
| | very unhelpful | quite unhelpful | neither helpful nor unhelpful | | quite helpful | very helpful | |
| If you received any, how helpful did you find the written self-help material? | 0% | 0% | 22% | | 65% | 13% | |
| Questions | Response Type (%) Sample Size 97% (n=30) | | | | | | |
| | not at all confident | not very confident | unsure at this time | | quite confident | very confident | |
| How confident are you that the psychology service will be able to help you? | 3% | 7% | 23% | | 50% | 17% | |

N.B. Where n is less than 28, the data is missing because the patient felt that the question was not applicable to them (e.g. they had not received self-help information or they were not going to wait for psychological services).

Table 2: Percentage scores on the Psychologist Satisfaction Questionnaire.

| Questions | Response Type (%) Sample size 100% (n=53) | | | | | | |
|--|--|--------------------|------------------------------------|--------------|-----------------|----------------|--------------|
| | YES | | NO | | | | |
| Did you find the amount of time for assessment of this patient adequate? | 55% | | 45% | | | | |
| If no, would you have preferred? | | | 60 mins more | 30 mins more | 15 mins more | 15 mins less | 30 mins less |
| | | | 0% | 13% | 32% | 0% | 0% |
| Questions | Response Type (%) Sample size 100% (n=53) | | | | | | |
| | very dissatisfied | quite dissatisfied | neither satisfied nor dissatisfied | | quite satisfied | very satisfied | |
| How satisfied are you that you gained an adequate understanding of this patient's problem? | 2% | 4% | 5% | | 59% | 30% | |
| How satisfied are you that this patient has found this assessment beneficial? | 0% | 6% | 13% | | 74% | 7% | |
| Questions | Response Type (%) Sample size 72% (n=38) | | | | | | |
| | very unhappy | quite unhappy | neither happy nor unhappy | | quite happy | very happy | |
| How happy are you that this patient will be waiting some time before treatment commences? | 0% | 39% | 16% | | 32% | 13% | |

N.B. Where n is less than 53, the data is missing because the question was not applicable to the patient (i.e. the patient was not going to wait for treatment).

Table 3: Percentage scores on the GP Satisfaction Questionnaire

| Questions | Response Type (%) Sample Size (n=14) | |
|--|---|-----|
| | YES | NO |
| Do you find ‘initial assessment prior to waiting’ preferable to the ‘waiting list system’ more usually employed by the psychology service? | 100% | 0% |
| Do you think that initial assessment prior to waiting is a better service for your patient? | 100% | 0% |
| Would you be more likely to refer patients if you knew they would be assessed quickly? | 86% | 14% |
| Questions | Response Type Sample Size 78% (n=11) | |
| | YES | NO |
| Does the feedback form given after assessment provide an adequate amount of information? | 100% | 0% |
| Does the feedback form, completed after assessment, provide the appropriate type of information? | 100% | 0% |

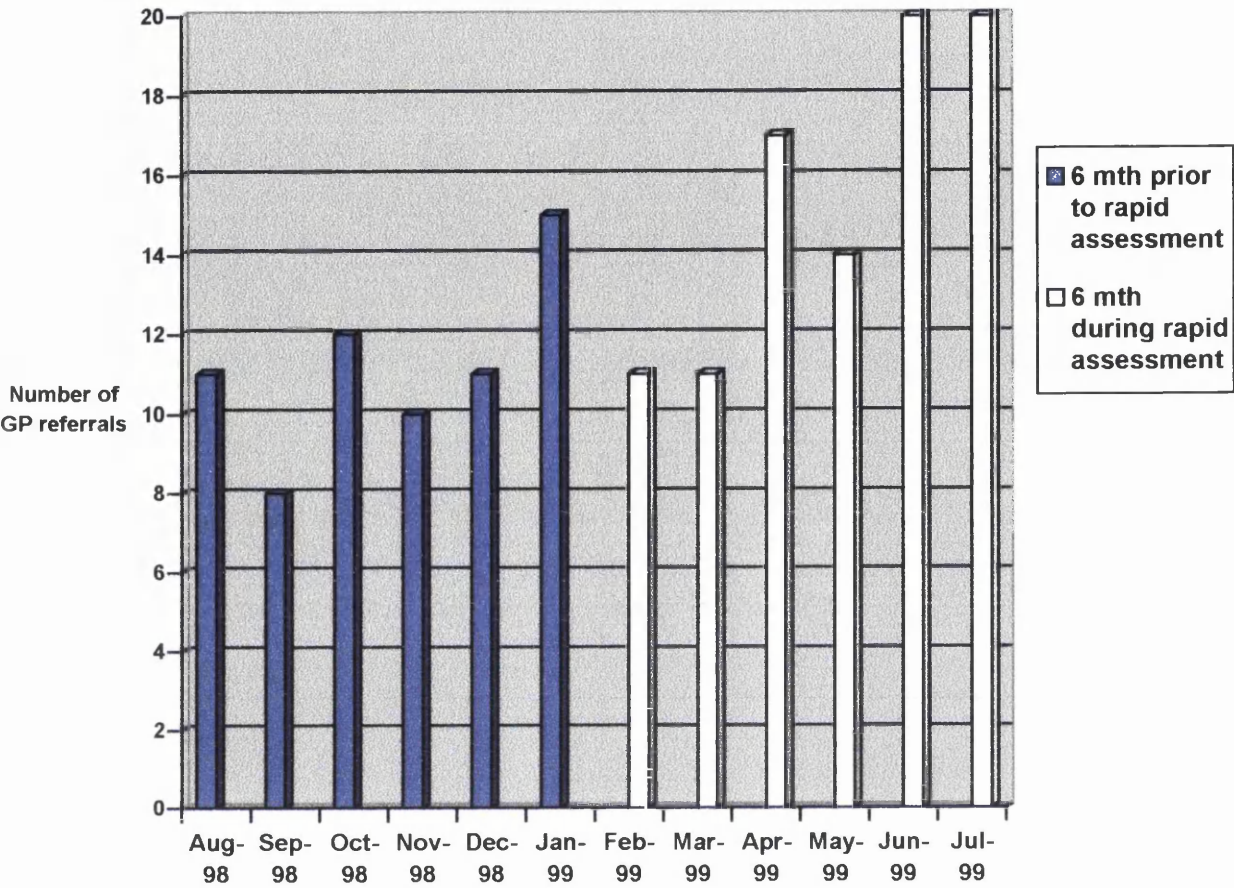
Table 4: Percentage and raw scores of patients receiving each outcome of assessment appointments

| Outcome | Percentage of patients (%) | Number of patients (n) |
|------------------------------|----------------------------|------------------------|
| Waiting for treatment | 72 | 38 |
| Urgently requiring treatment | 5 | 3 |
| Urgent court report | 4 | 2 |
| Not requiring treatment | 13 | 7 |
| Referred for group treatment | 4 | 2 |
| Referred on to CPN service | 2 | 1 |

Table 5: Records of service delivery statistics 6 months prior to the initial assessments and during the first six months of the initial assessment period

| Statistics | Time Period | |
|--|---|--------------------------------|
| | 6 months <i>prior</i> to initial assessment | 6 months of initial assessment |
| Mean monthly waiting time for initial appointments | 12 weeks | 3 weeks |
| Total non-attendance at initial appointments over 6 months | 13 | 2 |
| Mean monthly referral rate | 11.2 months | 15.5 months |

Figure 1:
GP referral rate 6 months prior to the initial assessment
and during the first 6 months of the initial assessment period



CHAPTER 2: LITERATURE REVIEW

**Emotional understanding, self-perceptions and depression
in high-functioning individuals with an autistic spectrum disorder.**

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ABSTRACT

This literature review explores research demonstrating that high-functioning children with an autistic spectrum disorder are capable of greater social and emotional understanding than predicted by contemporary theories of autism. It describes hypotheses that such individuals apply their cognitive abilities to develop social and emotional understanding, and reviews research suggesting that this understanding promotes more accurate self-appraisal and self-awareness, leading to more negative perceptions of self-competence. It argues that similar factors, relating to negative self-perceptions, may also be important in the development of depression, for these high-functioning children and adolescents with autistic spectrum disorders. The review highlights the importance of future research exploring the correlates and risk factors for depression in this population. As a starting point, it recommends exploration of the relationship between emotional understanding, negative self-perceptions and depression.

Keywords: Asperger syndrome; depression; emotional understanding; high-functioning autism; self-awareness; self-perceptions.

INTRODUCTION

Autism is a Pervasive Developmental Disorder (PDD) of the brain. The causes of the disorder are still unknown, but a strong genetic component and other biological factors have been implicated (Bailey, Philips & Rutter, 1996). Children who are classified as having autism, within ICD-10 (World Health Organisation: WHO, 1993) and DSM-IV criteria (American Psychiatric Association: APA, 1994), display marked abnormalities in their capacity for social interaction, in communication and language development, and in the development of symbolic play. In addition, they display restricted, repetitive patterns of activities and interests from infancy.

This spectrum of disorders can occur in conjunction with a range of intellectual abilities. Although the majority have a learning disability, 5-30% of the autistic population are reported as functioning within normal intelligence levels (DeMyer, 1979; Freeman et al., 1985; Rutter & Schopler, 1987) and are often referred to as "high-functioning", because of their normal range cognitive abilities. In cases where this spectrum of disorders are evident without intellectual disability or language delay, the variant of autism which is now labelled Asperger syndrome, may be the most appropriate classification. However, Asperger syndrome is still a controversial diagnostic category demonstratng significant overlap with autism (see Frith, 1991), and almost indistinguishable from those individuals described as having high-functioning autism (Gilchrist et al., 2001).

The present review is concerned with all individuals with an autistic spectrum disorder who have cognitive abilities within the normal range, regardless of diagnostic classification. It will

review, therefore, the literature relating to both groups (autism and AS), supporting the view that autistic disorders present on a continuum, across a range of ages, developmental stages, cognitive abilities, and individual symptom presentations.

This paper focuses on research exploring social and emotional understanding, self-perceptions and depression in children with an autistic spectrum disorder, who demonstrate cognitive abilities within the normal range. Its central objective is to highlight the knowledge which we currently have regarding the impact of increased self-awareness for these individuals, and to identify areas for future research. Initially, the review will present the research available pertaining to the description and definition of social and emotional deficits in autism, together with the impact which these difficulties are hypothesised to have on autistic individuals' development of emotional understanding and self-awareness. It will then describe literature relating to the presentation of these difficulties within high-functioning children and adolescents with an autistic spectrum disorder, with particular attention to research that has examined the relationship between cognitive abilities, emotional understanding and perceptions of self-competence within this population. The review will conclude with a discussion of important questions, which should be addressed by future research.

SOCIAL AND EMOTIONAL UNDERSTANDING DEFICITS IN AUTISM

Social and emotional understanding deficits have been repeatedly described in persons with autism (Gillham et al., 2000; Wing, 1988). Although, some social skills emerge over time, even higher-functioning adults continue to have major problems in social relationships (Volkmar & Cohen, 1985). Kanner first describing early infantile autism in 1943, regarded the social dysfunction and unusual response to the environment as the two essential features of the

syndrome. Diagnostic and assessment instruments developed for autism typically emphasise social factors (Parks, 1983), as do current diagnostic criteria for the disorder (APA, 1997). Although considered to be essential aspects of the syndrome definition, there has been a tendency to view social difficulty as secondary to other problems, hence the development of theoretical models that focus on the social deficit per se has been hindered. However, over the past two decades, a substantial body of research relating to social functioning in autism has emerged, and a number of theoretical models have developed which ascribe central significance to autistic children's interpersonal and social difficulties (Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1983; Hobson, 1990; 1991; 1993; Russell, 1996).

Description of social and emotional understanding deficits

Social deficits commonly observed in children with autism include: an absence of attachment behaviours (Lord, 1993), and of social behaviours in general (Klin & Volkmar, 1993); difficulties recognising and producing facial displays of emotion (Yirmiya et al., 1989); delays in the development of expressive language (Paul, 1987); difficulties developing a series of behaviours known as joint attention (Mundy et al., 1994); and deficits in the area of imitation and play (Smith & Bryson, 1994), particularly symbolic play (Stone et al., 1990). It is in this area of joint attention and social referencing that the most dramatic deficits in childhood autism occur (Sigman et al, 1986; Loveland & Landry, 1986). Joint attention refers to the ability to share the psychological space of another through mutually co-ordinated interaction (Stern, 1985). Social referencing, thought to occur following the first 6 months of life, describes the movement from dyadic face-to-face to triadic interactions that incorporate an outside object or event. This movement is thought to represent the beginning of the child's attempts to understand him/herself and others. A lack of joint attention, and recognition of the perceptions

and knowledge of others (displayed by individuals with autism), has devastating consequences for interpersonal relationships, social and emotional understanding and self-awareness.

Social and emotional understanding and high-functioning individuals with autism

As described earlier, autistic disorders exist on a spectrum, whereby there is dramatic variation between the abilities and limitations displayed by individuals with autism, who are young and have a learning disability, and those who are older, and of average or above average intelligence (Yirmiya & Sigman, 1991). Although still demonstrating qualitative impairments in social and emotional domains, high-functioning individuals with autism display a greater capacity for emotional expression and responsiveness (Ozonoff, Pennington & Rogers, 1991). Research has suggested that members of this high-functioning group are able to distinguish between emotions and to recognise expressions as reflections of a person's internal state (Thompson, 1989). They are able to describe their own experiences of simple emotions, such as happiness, sadness, anger, and fear, as well as complex emotions such as embarrassment and pride (Capps, Yirmiya & Sigman, 1992). They have also demonstrated the ability to label complex facial expressions in pictures that require knowledge and understanding of social cues (Capps, Yirmiya & Sigman, 1992; Van Lacker, Cornelius & Needleman, 1991). High functioning individuals with autism have also performed remarkably well on laboratory measures of empathy (Yirmiya et al., 1992). In comparison also to younger learning disabled children with autism who avoid, or ignore emotional displays, Yirmiya and colleagues found that high-functioning individuals were highly attentive and emotionally expressive, whilst watching video taped vignettes which depicted children experiencing a range of emotions. These abilities present a challenge to contemporary theories of autism, which hypothesise that innate social-cognitive deficits would constrain these abilities (e.g. Theory of Mind).

Theories

There are two main theories of autism that account for this unusual social presentation which ascribe central significance to autistic children's limitations in self-other experience, and they each predict corresponding deficits in the formation of concepts of self and of other, for these individuals.

One of the main theoretical frameworks which has developed, and which accounts for the unusual social presentation in autism is the *Theory of Mind* account (Leslie, 1987; Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1983). The *Theory of Mind* (ToM) hypothesis proposes that social deficits in autism are related to a fundamental cognitive deficit, a failure to attribute mental states to oneself and to others. The theory proposes that people with autism lack the ability to impute mental states in others (mind read), resulting in an inability to understand and predict behaviour. Research on the ToM hypothesis has supported suggestions that autistic individuals have limitations in conceptualising thought and belief (e.g. Baron-Cohen, Leslie & Frith, 1985), desire and pretence (e.g. Baron-Cohen, 1991), and feeling states (e.g. Capps, Yirmiya & Sigman, 1982).

Baron-Cohen's more recent work (Baron-Cohen, 1995) describes four components of mind reading which allow normally developing infants to develop the theory of mind mechanism at about 18 months. These components allow the individual to understand communication, such that they can proceed on the basis of what the speaker intends rather than on what has been stated literally. The first component is an Intentionality detector, which is hypothesised as a perceptual device for interpreting motion in terms of approach and avoidance. This is thought to be intact in autism. The Eye direction detector, the second component, is not thought to be an

automatic skill for individuals with autism. Essentially, this mechanism is said to determine that eye direction equals seeing what they are directed at and, therefore, also computes whether eyes are directed towards the self. The shared attention mechanism, responsible for the development of joint attention and triadic interactions described earlier (see page 31), coordinates the first two components, and leads to the emergence of the ToM mechanism, which enables understanding and prediction of the behaviour of others.

Hobson (1990, 1991, 1993) provides an alternative account to understand the social deficits present in autism. He asserts that individuals with autism do not lack a theory of mind per se, but lack knowledge of persons with minds. He suggests that only through their involvement in personal relationships do children arrive at concepts of themselves and of other people. Other authors (see Meltzoff & Gopnik, 1993; Rogers and Pennington, 1991) similarly propose that the fundamental deficit in autism lies in the construction and coordination of social representations of self through the identification of patterns of similarity between self and other, commonly developed through the process of imitation. Russell (1996) also suggests that the individual with autism has limited experience of acting alongside others and thus has impoverished psychological awareness of self and others. Central to each of these accounts, is the thesis that primary limitations in interpersonal relatedness are a source of autistic individuals deficient psychological concepts and self-understanding.

Challenges to Theory of Mind

Theory of Mind is perhaps the most widely researched of the contemporary theories of autism, however, it has a number of fundamental difficulties. ToM is good at explaining the social presentation in autism, but has been unable to adequately explain other features of autism such

as obsessional preoccupations, insistence on sameness and routine, attention to fine detail or fragmentary information processing, and special skills (Frith, 1989). Additionally, tests of ToM are predominantly experimental and have rarely been evaluated using naturalistic observations. Those studies that do utilise naturalistic methods have found that individuals with autism may pass 'paper' or artificial tests of ToM but still have difficulties in a natural setting (e.g. Roeyers, 2001). Similarly, attempts to teach ToM skills tend to be successful in increasing autistic children's performance on artificial tasks, but again do not generalise to real life situations (e.g. Ozonoff & Miller, 1995). The relevance of ToM is questionable if it cannot account for observable, real life behaviour.

Experimental studies with children and adults with autistic spectrum disorders largely support the ToM hypothesis. However, a key requirement of a good theory is its applicability to all members of a group. ToM experiments by their very nature require children to have a level of cognitive and verbal skill. They are, therefore, often not transferable and not applicable to non-verbal and less cognitively able individuals. High-functioning individuals with autism and AS also present a challenge to the theory of mind. A significant number of high-functioning adolescents and adults with autism or AS have been found to pass relatively complicated tests of ToM (e.g. Baron-Cohen et al., 1997; Happe, 1994; Jolliffe & Baron-Cohen, 1999; Ozonoff, Pennington & Rogers, 1991; Roeyers et al., 2001; Tager-Flusberg & Sullivan, 1995). The relevance of Theory of Mind to high-functioning individuals with autism has been questioned on the basis of these research findings. (See section below for further discussion of these research findings).

HIGH-FUNCTIONING INDIVIDUALS WITH AUTISM

Social and emotional understanding

As described earlier, autistic disorders exist on a spectrum, whereby there is dramatic variation between the abilities and limitations displayed by individuals with autism, who are young and have a learning disability, and those who are older, and of average or above average intelligence (Yirmiya & Sigman, 1991). Although still demonstrating qualitative impairments in social and emotional domains, high-functioning individuals with autism display a greater capacity for emotional expression and responsiveness (Ozonoff, Pennington & Rogers, 1991). Research has suggested that members of this high-functioning group are able to distinguish between emotions and to recognise expressions as reflections of a person's internal state (Thompson, 1989). They are able to describe their own experiences of simple emotions, such as happiness, sadness, anger, and fear, as well as complex emotions such as embarrassment and pride (Capps, Yirmiya & Sigman, 1992). They have also demonstrated the ability to label complex facial expressions in pictures that require knowledge and understanding of social cues (Capps, Yirmiya & Sigman, 1992; Van Lacker, Cornelius & Needleman, 1991). High functioning individuals with autism have also performed remarkably well on laboratory measures of empathy (Yirmiya et al., 1992). In comparison also to younger learning disabled children with autism who avoid, or ignore emotional displays, Yirmiya and colleagues found that high-functioning individuals were highly attentive and emotionally expressive, whilst watching video taped vignettes which depicted children experiencing a range of emotions. These abilities present a challenge to contemporary theories of autism, which hypothesise that innate social-cognitive deficits would constrain these abilities (e.g. ToM).

The Theory of Mind (ToM) account (Leslie, 1987; Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1983), referred to earlier, defines the autistic condition as a social-cognitive deficit a failure to attribute mental states to oneself and to others. However, a significant number of high-functioning adolescents and adults with autism or AS have been found to pass relatively complicated tests of ToM (e.g. Baron-Cohen et al., 1997; Happe, 1994; Ozonoff, Pennington & Rogers, 1991; Tager-Flusberg & Sullivan, 1995). Research, using advanced but static mind-reading tasks, has found mixed evidence for social-cognitive deficits. Some have been able to detect subtle differences between high-functioning subjects with autistic spectrum disorders, and a normally developing control group (Baron-Cohen et al., 1997; Happe, 1994; Jolliffe & Baron-Cohen, 1999). Others having detected no significant difference, have concluded that the mind-reading deficit may be apparent only when a sufficiently complex naturalistic method is used (Roeyers et al., 2001).

These findings cannot be taken as evidence of intact social-cognitive functioning. Indeed, when considered together, they demonstrate merely that individuals with autism or AS, who have general cognitive abilities within the normal range, are capable of demonstrating heightened (although still impaired) emotional understanding and some advanced ToM skills on artificial tasks. What they do suggest, however, is that there may be a direct relationship between mind-reading skills and cognitive and verbal skills. It seems possible that higher intellectual functioning does compensate for emotional deficits, to the extent that the abilities which develop reflect extraordinary attempts to overcome these deficits, rather than an absence of the deficits (Capps, Sigman & Yirmiya, 1995). The questions of clinical relevance concern how these emotional abilities develop, and the implications of this heightened emotional understanding for this group of individuals. In particular, the implications of these heightened

abilities upon other areas of psychological functioning require exploration, for example, a greater degree of understanding may advance self-knowledge and self-awareness, promoting social comparison.

Emotional understanding and self-perceptions

Autobiographical writing has provided a rich source of information on how individuals with autism view themselves in relation to others and how they come to understand their differences (Cohen, 1980; Grandin, 1984; Happe, 1991). These writings have suggested significant levels of self-awareness from middle childhood. However, there is little empirical information available on the implications of heightened awareness on self-perceptions in this population. Capps, Sigman & Yirmiya (1995), in the only published study in this area, set out to illuminate how high-functioning autistic children and adolescents applied their intellectual strengths to gain access to greater levels of self-awareness and emotional understanding. In this study, these authors administered questionnaire and interview measures of perceived competence, emotional understanding and IQ to eighteen children with autism and twenty normally developing children, aged between nine and sixteen years.

Capps and colleagues explored the hypotheses that greater self-awareness (as reflected by more accurate self-perceptions) would be mediated by higher intelligence and the ability to read and share the emotions of others. The measure of self-awareness utilised was the Perceived Competence Scale for Children (PCSC: Harter, 1982). This measures a child's sense of competence in four different domains, including cognitive, physical, and social competence, and general self-worth. Parents were also asked to provide individual ratings of each child's adaptive behaviour, on the Vineland Adaptive Behaviour Scale, to allow an objective measure

of children's social and adaptive competencies. Emotional understanding was measured in two ways: the first, was by means of an interview which assessed each child's ability to communicate about his/her emotional experiences (Capps, Yirmiya & Sigman, 1992); and the second, being a measure of each child's ability to label and empathise with the emotions of others, using taped vignettes of child protagonists experiencing a number of emotions (Yirmiya et al., 1992). Each measure of emotional understanding required to be scored by raters, although inter-rater reliability was not reported in the study. In order to attempt to determine the impact of hypothesised awareness of social shortcomings, Capps, Sigman & Yirmiya (1995) examined whether more negative self-perceptions might be reflected in the frequency of the child's display of negative affect, therefore, parents were asked to report on each child's experience of negative affect over the course of their daily life, using the Emotion Behaviour Checklist (Izard et al., 1974).

Findings revealed that the children and adolescents with autism reported lower estimates of their overall self-worth, and perceived themselves to be less competent than did their non-autistic peers in social and physical, but not cognitive domains. Those young people who viewed themselves as less socially competent also had gained higher IQ scores and demonstrated greater emotional understanding and more adaptive social behaviour (as rated by their parents). The authors concluded that more negative perceptions of social competence represented more accurate perceptions, which were likely to have been mediated by higher IQ and social and emotional understanding. Those children who viewed themselves as less competent were also reported as having demonstrated higher levels of negative emotions. The authors wondered whether frequent expressions of negative affect might indicate the presence

of a mood disorder. Unfortunately, however, they had not employed a measure of depression within their research design to explore this facet.

The study demonstrated that the more socially and emotionally able children with autistic spectrum disorders were reporting more negative self-appraisals. The results raise a number of questions to be addressed by future research, regarding the implications of greater self-awareness and negative self-appraisals, in relation to psychological adjustment and mood disorders, specifically.

Emotional understanding, self-perceptions and depression

At the moment we know very little about the presentation, course and treatment of mood disorders within the autistic population. As recently as five years ago, there were many anecdotal reports, but very few systematic studies on the topic. However, over the last decade, there has been growing support for the diagnostic validity of mood disorders within the autistic population (see Lainhart, 1999). Family studies have revealed an increased prevalence of affective disorders in first degree relatives of individuals with autism and co-morbid clinical depression (Abramson et al., 1992; Piven et al., 1991; Smalley et al., 1993). Community and clinic-based research studies have reported higher levels of comorbid mood disorder with adults (Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998; Lainhart & Folstein, 1994), and adolescents with AS (Ghaziuddin & Greden, 1998; Green et al., 2000; Kim et al., 2000), and generally conclude that these individuals are at greater risk for developing mood disorders than the general population. Reviews of the literature (Lainhart, 1999), have highlighted the increasing importance of identifying and understanding correlates and risk factors for

depression within this population. However, to date, there have been no published studies formally addressing this area of research within autism or AS.

One of the central hypotheses to emerge regarding the aetiology of depression amongst individuals with autistic spectrum disorders, suggests that depression reflects increased insight amongst those with milder impairments (Capps, Sigman & Yirmiya, 1995; Happe, 1994; Wing, 1988). A similar argument has evolved within the learning disability literature to account for the higher incidence of depression amongst individuals who are mildly learning disabled as compared to those who are moderately or severely learning disabled¹ (Benson and Ivins, 1992; Reiss, 1985; Reiss & Rojahn, 1993). Apart from cognitive ability, little is known of the other psychosocial factors, which might mediate insight and potentially mediate depression. Capps Sigman & Yirmiya, (1995) found striking evidence that increased levels of social and emotional understanding were correlated with more accurate self-appraisals (insight), amongst high-functioning children and adolescents with autism. Furthermore, those individuals who reported more negative self-appraisals were also observed to express increased negative affect. This raised a question regarding whether more frequent expressions of negative affect might relate to an affective disorder. Lewinsohn, Gotlib & Seeley (1997), in their large-scale study, found a strong relationship between negative self-appraisals and adolescent depression, within the normally developing population. Future research is urgently required, to explore the relationship between these factors with a high-functioning adolescent population with autism or AS, who are likely to be at increased risk of negative self-appraisals and depressive disorders.

¹ The author acknowledges that these results could simply reflect the insensitivity of current measures of depression, in detecting symptoms among individuals with limited language ability, however, this debate is beyond the scope of this paper.

FUTURE RESEARCH DIRECTIONS

Emotional understanding, self-perceptions and depression

Future research should extend our present knowledge of this area by exploring the hypothesised relationship between emotional understanding, negative self-perceptions and depression. Such research would replicate and extend the Capps, Sigman & Yirmiya (1995) study, whilst addressing a number of methodological issues from this study. Firstly, as alluded to earlier, rather than exploring the relationship between emotional understanding, self-competence and observed expressions of negative affect, such a study should measure the relationship between these factors and depressive symptoms. The Emotion Behaviour Checklist (Izard et al., 1974), employed in the Capps et al. (1995) study to measure observations of a child's expression of negative affect, is a relatively weak measure, with limited reliability and validity, and recording little information of any clinical relevance. Simply displaying negative affect is not in itself evidence of a mood disorder, hence, using a standardised psychometric measure of childhood depression in future research would seem to be more pertinent. Employing this approach could explore whether high-functioning children and adolescents with autism, who have greater emotional understanding and more negative self-perceptions, may also experience a greater degree of depressive symptoms.

At present, there are no published papers discussing the use of self-report, psychometric measures of depression with children and adolescents with autistic spectrum disorders. Previous research has involved the use of structured diagnostic interviews, relying largely on parental reports (Ghaziuddin & Greden, 1998; Green et al., 2000; Kim et al., 2000). These instruments are likely to be insensitive to childhood symptoms of depression within this

population for two main reasons. Firstly, they require large amounts of verbal self-report (thus ignoring the fact that individuals who have autistic spectrum disorders may have difficulty with verbal communication formats) and secondly, parental reports of depressive symptoms are notoriously insensitive (Canning, et al., 1992, 1993; Klein, 1991).

Given that high-functioning children with autism and AS have demonstrated the ability to self-report on a standardised self-competence questionnaire (PCSC), there is little reason to assume that they would have more difficulty with a standardised depression scale, if it were presented in an appropriate format. As such a measure has not been validated with young people with autistic spectrum disorders, a scale with a parallel parent-form would be most useful. Clearly, given the lack of standardisation with this group, results from any child depression scale would require to be interpreted with some caution. However, they could also provide invaluable information regarding the nature of self-report depressive symptoms in an autistic population, and of the relationship between depressive symptoms and other psychosocial factors such as emotional understanding and perceived self-competence.

SUMMARY AND CONCLUSIONS

Although there have been tremendous advances in our understanding of high-functioning children with autistic spectrum disorders, there is still much to learn about the psychological needs of these individuals. Future research is urgently required to enhance understanding and identification of psychological distress within this population. This review has highlighted the need for an initial, exploratory study to determine the relationship between depressive symptoms, negative self-perceptions and heightened emotional understanding, with high-

functioning young people with autism or AS. This would provide a preliminary contribution to research into the psychosocial correlates and risk factors for depression.

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CHAPTER 3: PROPOSAL FOR MAJOR RESEARCH

The relationship between perceived self-competence, emotional understanding and depression in high-functioning children with autism.

Kirsty A. Dalrymple

**Prepared in accordance with guidelines for application for a mini-project grant in Health Services Research SOHHD - Chief Scientist Office
(Appendix 3.1)**

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Title: *The relationship between perceived self-competence, emotional understanding and depression in high-functioning children with autism*

Summary

This research aims to assess the self-perceptions and emotional understanding of high-functioning children with autism, and the relationship between these and reported levels of depression. It draws on a major theoretical perspective, hypothesising a cognitive deficit in the formation of concepts of self, for autistic individuals, namely the 'theory of mind deficit model' (Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1993; Leslie, 1987). Only two published controlled studies have explored this hypothesis directly, one assessing the self-concepts of children and adolescents with autism (Lee & Hobson, 1998) and the other the perceived self-competence of adolescents with autism (Capps, Sigman & Yirmiya, 1995). In contrast with the predictions of the model, these studies revealed that high-functioning children with autism were able to compare themselves to others, and were aware of their shortcomings. It was proposed that these individuals utilised their cognitive abilities to develop emotional and social understanding beyond the predicted level for their disorder, enhancing their self-awareness.

This research will explore further the relationship between self-perceptions and heightened emotional understanding and social adaptation. It will also examine whether symptoms of depression are correlated with negative perceptions of self-competence in the same way as with normally developing children (Lewinsohn, Gotlib & Seeley, 1997). In order to do this it will compare the performance of two groups of participants. One group will be high-functioning children with an autistic spectrum disorder, and the other, normally developing children

matched for chronological age and verbal mental age. Standardised questionnaire measures, for children and parents, will be used with both groups, to answer the questions outlined above. Research will be carried out in the West of Scotland, under circumstances where both ethical approval and parental and personal consent have been obtained. Results will be interpreted in line with current theories of autism, and with research in the child and learning disability field, suggesting a correlation between negative self-perceptions and depression. The findings are intended to add to our understanding of the self-perceptions of high-functioning children with an autistic spectrum disorder, and of the implications of greater self-awareness for their psychological wellbeing.

Introduction

Social deficits have been repeatedly described in persons with autism (Gillham et al., 2000; Wing, 1988). There are a number of theories of autism which account for this unusual social presentation that ascribe central significance to autistic children's limitations in self-other experience. Each predicts corresponding deficits in the formation of concepts of self and of others, for these individuals.

One major theoretical perspective is the Theory of Mind (ToM) account of autism (Leslie, 1987; Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1983). It ascribes these social deficits to a fundamental cognitive deficit, an innate inability to appreciate one's own and others mental states. Research in this area has supported suggestions that autistic individuals have limitations in conceptualising thought and belief (e.g. Baron-Cohen, Leslie & Frith, 1985), desire and pretence (e.g. Baron-Cohen, 1991), and feeling states (e.g. Capps, Yirmiya & Sigman, 1992). These difficulties in understanding and describing behaviour in psychological terms (Tager-Flusberg & Sullivan, 1994), would seem capable of producing marked impairments in their conceptions of themselves in relation to others. However, these impairments have yet to be explored in detail.

The results of research relating to these individuals' self-conceptions and self-understanding is scarce. Lee and Hobson (1998) addressed the question as to whether individuals with autism were unusual in the nature of the concepts they have about themselves, as compared to a control group. Their results advocated a specific deficit located within the social domain, but not within physical, active or cognitive domains. This suggested that, rather than demonstrating

a global deficit in self-concept, certain individuals with autism might be selectively impaired in their conceptions of themselves, within social or interpersonal areas (Hobson, 1990; Loveland, 1993; Rogers & Pennington, 1991). Capps, Sigman & Yirmiya (1995) used the Perceived Competence Scale for Children (Harter, 1982) and found that autistic children provided lower estimates of their overall self-worth, perceiving themselves to be less competent than their non-autistic peers did in social and physical, but not cognitive domains. Furthermore, those children who reported lower social competence were perceived by their parents to be better adjusted socially and demonstrated greater emotional understanding, than those children who reported greater social competence. The authors raised the possibility that heightened awareness of social weaknesses, displayed by the most intelligent autistic children, represented more accurate self-appraisals. It was hypothesised that these self-appraisals were possible, because the children applied their cognitive abilities to develop greater emotional and social understanding. It was possible that these children had developed sufficient theory of mind skills, thus reducing the impairment inherent in their disorder.

The results of this study are consistent with autobiographical writings by individuals with autism, suggesting a stark awareness of differences from others, from around middle childhood (Cohen, 1980; Grandin, 1984; Happe, 1981). Capps, Sigman & Yirmiya (1995) introduced questions regarding the implications of this heightened awareness and understanding on self-esteem and psychological wellbeing. The literature pertaining to individuals with a learning disability, reports that the incidence of depression is higher among individuals who are mildly learning disabled than among those who are moderately or severely learning disabled (Benson & Ivins, 1992; Reiss, 1985; Reiss & Rojahn, 1993). Similarly, these authors comment that this relationship may be a function of increased frustration from greater awareness of their

limitations. Furthermore, research undertaken investigating the psychosocial correlates specific to adolescent depression has highlighted self-consciousness and low self-esteem as central variables differentiating depression from non-affective disorders (Lewinsohn, Gotlib & Seeley, 1997). The relationship between these variables for high-functioning children with autism, who are likely to experience heightened awareness of social differences, has yet to be investigated and is a central aim of this research. Another reason for exploring the correlates of depressive symptoms within this population relates to the recent reports of high levels of comorbidity of mood disorder with individuals with Asperger syndrome (Ghaziuddin et al., 1998; Ghaziuddin & Greden, 1998; Ghaziuddin & Tsai, 1991). It is becoming increasingly important, therefore, that clinicians can identify symptoms of depression within this population.

This investigation aims to replicate the research of Capps, Sigman & Yirmiya (1995) by exploring the self-perceptions and emotional understanding of high-functioning children with an autistic spectrum disorder. It also hopes to develop their research by investigating the relationship between these factors and reported levels of depression.

Aims and Hypotheses

This research has the following aims:

- To assess whether children with autistic spectrum disorders, who demonstrate greater emotional understanding, will have greater awareness of their differences from others, and report more negative perceptions of self-competence.
- To determine whether more negative perceptions of self-competence are related to more severe symptoms of depression, as have been established in previous studies of non-autistic, clinically depressed adolescents.

- To investigate the relationship between high-functioning autistic children's perceptions of their own social abilities, and their parents' perceptions of the children's social adaptation.
- To investigate the relationship between high-functioning autistic children's reports of their experience of depressive symptoms, and their parents' observations of the children's experience of depressive symptoms.
- To compare the performance of the two groups of participants in relation to the measures included in the study.

The following predictions can be made from the limited research available in this area:

- Children with an autistic spectrum disorder will perceive themselves to be less competent than members of a non-autistic control group, in all domains other than cognitive domains.
- Children with an autistic spectrum disorder, who perceive themselves to be less competent will have greater emotional understanding, and report higher levels of depressive symptoms.
- Children with an autistic spectrum disorder, who perceive themselves to be less socially competent, will be reported by their parents as demonstrating more socially adaptive behaviour.
- The group of children with an autistic spectrum disorder will obtain significantly lower scores on measures of self-competence, emotional understanding and socially adaptive behaviour, and significantly higher scores on the depressive symptom measure, as compared to a normally developing comparison group.

Plan of Investigation

Participants

All participants will be children or adolescents, aged between 10 and 17, who currently attend mainstream school and have verbal abilities within the normal range. One group will have received a diagnosis of autism or Asperger syndrome and the comparison group will be normally developing children and matched for chronological age, gender and verbal mental age, with the participants with and autistic spectrum disorder. Inclusion criteria for the comparison group also includes having no family history of autism/AS, no past or current record of needs, and no past or current psychiatric diagnosis. Children with an autistic spectrum disorder will be included in the study if, they have received a diagnosis of an autistic spectrum disorder from a recognised clinician² (e.g. Paediatrician, Clinical Psychologist, Psychiatrist), and they score above the cut off on parents reports on the Autism Spectrum Screening Questionnaire (ASSQ: Ehlers, Gillberg & Wing, 1999). The ASSQ is the *only* screening measure designed for school-age children with Asperger syndrome or high-functioning autism for which detailed reliability and validity data are available. The children with an autistic spectrum disorder must have scores above the cut-off of 19 (the optimal parent score for identifying autistic spectrum disorders) to be included in the study and the comparison group must have a score below 5.

Recruitment

Participants with an autistic spectrum disorder will receive information about the study (Appendix 3.2) through their membership at local branches of the National Autistic Society

² There are currently few valid diagnostic instruments specifically for Asperger syndrome, which can be used as screening measures (see Howlin, 2000). There is also some debate surrounding who is eligible to make or confirm diagnoses of autism and AS according to current diagnostic criteria. It was thought, therefore, that the most reliable and valid diagnosis would be

(NAS). Participants in the comparison group will receive information through their child's school. The information will invite interested parties to contact the researcher and/or return consent forms (Appendix 3.2) if they are interested in taking part. Both the young person and the parent, wishing to take part in the study must sign the consent form prior to inclusion.

Measures³

Measure used to match samples: British Picture Vocabulary Scale - II (Dunn, Dunn & Whetton, 1997).

Child Measure: The BPVS is one of the most widely used measures of verbal mental age in studies of children with autism. It is also widely used in clinical practice. Given that one aim is to ensure that the children are able to understand the questions posed to them, a measure of receptive vocabulary seemed appropriate. This measure will allow the groups to be matched for performance on the BPVS-II. Approximate administration time of 15 minutes.

Social Skills Measures: The Self-Perception Profile for Children (SPPC; Harter, 1985) – a revision of the Perceived Competence Scale for Children (PCSC; Harter, 1982); The Socialisation domain of the Vineland Adaptive Behaviour Scales - Survey Form (VABS; Sparrow, Balla & Cicchetti, 1984).

Child Measure: The SPPC (see Appendix 3.3) is a 36 item self-report instrument which measures children's perceived competence or self adequacy across six domains, these

conducted by a qualified clinician following a thorough multidisciplinary assessment. All participants had been diagnosed in this manner, prior to the study.

³ N.B. Copies of all measures that are not currently used in routine clinical practice have been appended (Appendix 3.3).

including: scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct, and global self-worth. It has high internal consistency, as well as good convergent, construct and discriminant validity. The PCSC was selected for the Capps, Sigman and Yirmiya (1995) study and, therefore, has been used successfully with children who have an autistic spectrum disorder. For each item, the respondent is asked which of two opposite statements is more applicable to him/her (e.g. in games and sports, some kids usually watch instead of play BUT other kids usually play rather than watch). Having selected which statement better applies to him/her the respondent is then asked the degree to which the statement is applicable, on a two-point scale, whether true OR sort of true. Scores are summed, affording a total of six subscale means, which will define a given child's profile. Approximate administration time of 15 minutes.

Parent Measure: The VABS is an interview which will be administered to parents to provide a measure of social and adaptive competencies, standardised scores with age equivalents being available in four domains: communication, daily living skills, socialisation, and motor skills. Since the socialisation domain is more applicable to this research, it will be used to provide an objective measure of adaptive social behaviour. The VABS has excellent reliability and validity (Cicchetti & Sparrow, 1981; Sparrow, Balla & Cicchetti, 1984), is widely used in routine clinical practice and has demonstrated utility in the assessment of children with autism (Capps, Sigman & Yirmiya, 1995; Volkmar et al., 1987). It has an approximate administration time of 15 minutes.

Emotional Understanding Measures: The Eyes Test (Baron-Cohen et al., 1998); Communication about own emotional experiences (Capps, Yirmiya & Sigman, 1992).

Child Measure: The Childrens Version of the Eyes Test (Baron-Cohen et al., 1998) has been reported as an advanced test of theory of mind developed for use with high-functioning adults with autism or Asperger syndrome (see Appendix 3.3). The task involves inferring a person's mental state solely from information revealed in photographs of a person's eyes. Each of 28 pictures is shown for 3 seconds and requires a forced choice response between two mental state terms printed under each picture. The maximum score on this test is 28. It has an approximate administration time of 10 minutes.

Child Measure: Communication about own emotional experiences (Capps, Yirmiya & Sigman, 1992). This is a measure of the ease with which a child can talk about his/her emotional experiences. Each child is asked to relate a time when he/she felt each of four emotions (sadness, happiness, embarrassment and pride). Prompting, in the form of repetition, is used when a child does not respond, or has difficulty responding. To measure the difficulty of the task, the number of prompts is counted, and latency of response timed. The measure is designed for use with children with autism and has demonstrated utility with this population. Approximate administration time is 10 minutes.

Depressive Symptom Measure: Childrens Depression Scale – Second Research Edition (CDS; Tisher & Lang, 1983).

Child Measure: The CDS has been selected, because it has a parallel form for parents and possesses high internal consistency (Bath & Middleton, 1985), high convergent validity and good test-retest reliability (Kazdin, 1981). The CDS is a 66 item, self-rated scale, which uses a

modified card-sort response format, with items individually listed on cards sorted by the child into one of five boxes labelled: very wrong, wrong, not sure, right, and very right. The CDS evaluates two broad factors, with 18 items comprising a 'positive affective experience subscale', and the remaining 48 items a 'depression subscale'. The positive affect scale includes one subscale of eight items (pleasure and enjoyment), with the remaining items described as miscellaneous. The depression subscale includes 5 subscales (affective response, self esteem, preoccupation with sickness and death, guilt, and loss of pleasure and enjoyment), along with 9 additional miscellaneous items. Approximate administration time of 20 minutes.

Parent Measure: The CDS – Adult Form (Tisher, 1995) consists of a separate set of cards reworded for use with parents, teachers or siblings. Whilst it is well-known that parent reports are not adequate for assessing internalising symptoms such as depression (Canning, et al., 1992, 1993; Klein, 1991), the combination of parent and child ratings have been selected in this instance, because the validity of the use of symptom depression scales of this kind with high-functioning children with an autistic spectrum disorder, has yet to be evaluated in the published literature. Approximate administration time is 10 minutes.

Design and Procedure

The research will involve interviewing children and their parents. Only children and adolescents who have received a diagnosis of autism or Asperger syndrome, and whose verbal ability is within average range on the BPVS-II will be included in the study. An initial brief interview will aim to assess specifically the child's suitability for the study and their ability to comprehend the questions posed by the assessment measures. Thus, prior to entry into the study, parents will be asked questions about their observations of the child's ability to

understand and respond to questions about themselves, with the children completing a measure of language comprehension (BPVS-II; Dunn, Dunn & Whetton, 1997). If these preliminary measures suggest suitability, participants will be entered into the study, in order to complete further measures.

The overall design of the study will be a between group design. Comparisons will be made between the two groups performance on each of the standardised measures outlined above. Within group comparisons will be made to compute the relationship between scores across the children's measures for each group, and to compute the relationship between scores across the measures of functioning administered both to children and parents.

Settings and Equipment

Participant children will be interviewed either at home or at school. Participant parents will be interviewed at home. The interviews will take place in a private room and will be carried out by one interviewer only. The overall administration time for child measures is 80 minutes and for parent measures is 20 minutes. Given the lengthy administration time for the child measures, children will be seen on two occasions in order to reduce fatigue, ensuring that session is kept to a maximum of 50 minutes.

Power Calculation

The study, which most closely matches this in terms of design and procedure, is that of Capps, Sigman & Yirmiya (1995). A power calculation based on data from this study was calculated using javastat available on the statPages.net web site. The calculations indicated that, in order to demonstrate an effect size of 0.4, with a significance level of 0.05, and power held at 0.8, the

study would require 12 child participants, 6 in each group, for a between-group analyses using t-tests. The calculations indicated that, for correlation tests, in order to demonstrate an effect size of 0.4, with a significance level of 0.05, and power held at 0.8, the study would require 32 child participants, 16 in each group. Therefore, the study will use the larger of these figures.

Data Analysis

Data will be collated during each interview and will be stored in a locked cabinet at the Department of Psychological Medicine. It will be analysed using quantitative data analysis methods comparing mean group responses on each task, involving the use of independent sample t-tests, and investigating the relationship between responses across measures within each group, using correlational analyses.

Practical Applications

The findings are intended to add to current understanding of the self-perceptions that high-functioning children with an autistic spectrum disorder have, and of the implications of greater emotional understanding and self-awareness on their self-perceptions and experience of depressive symptoms. The overlying suggestion, from the limited research undertaken in this area, is that enhanced self-awareness, for high-functioning individuals with autism, may lead to a greater focus on their failings within social situations. Clarifying whether this is the case is a necessary preliminary step. This project intends to examine this and the factors associated with greater emotional understanding and self-awareness, namely, whether the experience of more negative self-perceptions and symptoms of depression. The results will increase understanding of the psychological needs of these children and their susceptibility to negative self-evaluation and symptoms of depression. In so doing, it will also explore the psychosocial correlates of

depressive symptoms, with children with an autistic spectrum disorder, contributing to a very sparsely researched area, aiming to promote more appropriate identification and treatment of comorbid mood disorders within this population.

Timescale

Data collection will begin after ethical approval has been obtained, and is expected to last approximately 6 months, commencing in November 2000.

Ethical Approval

Ethical approval was obtained from Greater Glasgow Primary Care (NHS) Trust (GGPCT) Ethics Committee, in the first instance (Appendix 3.4). Ethical approval was also obtained from the National Autistic Society (NAS). At the request of GGPCT Ethics Committee, "Chairpersons approval", or an acknowledgement that full ethical approval is not required, will be sought from relevant health board Ethics Committees within the West of Scotland, prior to approaching local branches of the NAS within the health boards jurisdiction (Appendix 3.4). In order to recruit participants for the comparison group from a school within Greater Glasgow, additional approval (additional to that already obtained from GGPCT Ethics Committee) will be sought from Greater Glasgow Local Educational Authority.

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AMENDMENTS TO MAJOR RESEARCH PROPOSAL

One amendment to the original proposal was required. This entailed the following.

It was originally thought that control participants would be recruited from local schools within Greater Glasgow. GGPCT Research Ethics Committee initially approved this approach in October 2000. However, given that participants in the AS group were predominantly male, it was decided that a boys club may provide the opportunity to match samples more effectively. Approval was obtained from the Chief Executive of the Greater Glasgow Scout Council, and a local Glasgow Scout Group volunteered to assist with the project. Information was distributed anonymously through the leader of this group, and consent forms were returned to the researcher (see Appendix 3.2). Ethical approval in relation to this amendment was obtained from GGPCT Research Ethics Committee in February 2001, and is appended in Appendix 3.4.

CHAPTER 4: MAJOR RESEARCH PAPER

**Depression, self-perception and emotional understanding
in children and adolescents with Asperger syndrome.**

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**Prepared in accordance with guidelines for contributors to
The Journal of Child Psychology and Psychiatry and Allied Disciplines
(Appendix 4.1)**

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ABSTRACT

This study explored the implications of self-awareness for a group of 15 children and adolescents with Asperger syndrome (AS). It examined the relationship between the groups' scores on standardised measures of self-perception, emotional understanding, socially adaptive behaviour and depressive symptoms, and compared these scores to those of normally developing children, matched for age, gender and verbal mental age. The results support the central predictions of the study, advocating the thesis that young people with AS who develop improved emotional and social abilities are more likely to acquire insight into their differences and experience increased symptoms of depression. These results are congruent with autobiographical accounts (Kalen, 2000) and previous research with high-functioning children with an autistic spectrum disorder (Capps, Sigman & Yirmiya, 1995), demonstrating the relationship between raised social and emotional abilities and more accurate self-appraisals. The results also support the hypothesis that negative self-perceptions play a central role in the experience of depressive symptoms, in children and adolescents with AS, highlighting this variable as a potential risk factor for depression. Discussion focuses on the implications of these findings for clinical interventions and future research.

Keywords: Adolescent, Asperger syndrome, autism, children, depression, emotional understanding, self-awareness, self-perception.

Abbreviations: AS: Asperger syndrome; ASSQ; Autistic Spectrum Screening Questionnaire; BPVS: British Picture Vocabulary Scale; CDS: Child Depression Scale; OWNEE: Communication about own emotional experiences; SPPC: Self-Perception Profile for Children; VABS: Vineland Adaptive Behaviour Scale.

"When I was little, I had very little awareness of other people, let alone whether those people were teasing me. As my awareness increased, I also became increasingly aware of the social ostracism I was victim to. In early adolescence, things were so bad that I was seriously depressed and suicidal. For me, it was easier being oblivious and low-functioning than to be in my current high-functioning (autistic) state where I am aware of what I am not." (Kalen, 2000, p.4).

The narrative presented above is not unfamiliar to clinicians working with high-functioning individuals with autism or Asperger syndrome⁴ (Attwood, 1997). It describes how growing awareness of differences from others and awareness of social exclusion, can lead to disorders of mood and even suicidal thoughts, amongst high-functioning individuals with an autistic spectrum disorder. This degree of awareness or insight is surprising, given the emotional and social difficulties inherent in autistic spectrum disorders. However, it has often been suggested that these high-functioning individuals use their cognitive abilities to compensate for their social and emotional weaknesses and, hence, develop levels of awareness. Research has largely supported this claim, but we understand little of the implications of this awareness in relation to their self-perceptions or general psychological functioning. The suggestion from personal accounts (see Happe, 1991; Kalen, 2000), is that insight may promote more negative self-evaluation and depression. The purpose of this study is to investigate empirically the relationship between these factors for high-functioning children and adolescents with Asperger syndrome (AS).

⁴ Individuals with an autistic spectrum disorder, who have cognitive abilities within the normal range, are often referred to as high-functioning. Current diagnostic practice recognises Asperger syndrome as meeting the same criteria for autism, but with no history of language or cognitive delay. Depending on early language ability, these individuals with normal range cognitive abilities either receive a diagnosis of Asperger syndrome or high-functioning autism (APA, 1994; WHO, 1997). However, the distinction between the two groups appears to be largely academic, with the majority of studies finding no significant differences (see Gilchrist, et al., 2001).

Autobiographical writings, in general, have provided a rich source of information on how high-functioning individuals with autism and AS think and feel, and how they come to understand their differences from others (Grandin, 1984; Happe, 1991). These writings have suggested significant levels of self-awareness apparent from around middle childhood. Unfortunately, the research literature has been slow to explore psychological understanding and functioning within this population. Over the last decade, however, the following empirical findings have been reported.

Although still demonstrating qualitative impairments in social and emotional domains, high-functioning individuals with autism and AS are able to demonstrate considerable understanding both, of their own emotions (Capps, Yirmiya & Sigman, 1992), and those of others (Yirmiya & Sigman, 1991). Many can also recognise (Thompson, 1989) and label complex facial expressions, requiring knowledge and understanding of social cues (Capps, Yirmiya & Sigman, 1992; Van Lacker, Cornelius & Needleman, 1991). A significant number of high-functioning adolescents and adults who have autism or AS have also been found to pass relatively complicated tests of Theory Of Mind (e.g. Baron-Cohen et al., 1997; Happe, 1994; Ozonoff, Pennington & Rogers, 1991; Tager-Flusberg & Sullivan, 1994). The Theory of Mind (ToM) hypothesis (Leslie, 1987; Baron-Cohen, 1991; Baron-Cohen, Tager-Flusberg & Cohen, 1983), or Theory of Mind Mechanism (ToMM) as it has recently been re-conceptualised (Baron-Cohen, 1995), defines the autistic condition as a social-cognitive deficit, a failure to attribute mental states to oneself and to others. Studies with children and adults with autistic spectrum disorders, largely support this hypothesis. However, researchers using advanced ToM tasks have found mixed evidence of social-cognitive deficits with high-functioning individuals. Some have been able to detect subtle differences between high-functioning subjects with

autism and a normally developing matched control group (Baron-Cohen et al., 1997; Jolliffe & Baron-Cohen, 1999). Others have found no evidence of a significant difference and have concluded that the mind-reading deficit may be apparent only when a sufficiently complex naturalistic method is used (Roeyers et al., 2001).

Taken together, these findings demonstrate that individuals with autism or AS, who have general cognitive abilities, within the normal range, are capable of demonstrating reasonable emotional understanding and some advanced ToM skills on artificial tasks. They suggest also that there may be a direct relationship between mind reading and emotional skills, and cognitive abilities, supporting the earlier suggestion that these individuals utilise their cognitive abilities in developing social and emotional understanding. Despite the implications for clinical intervention, we know little of how the ability to read and interpret the emotions of others might affect the self-concept of these high-functioning individuals, who experience pervasive interpersonal difficulties.

Capps, Sigman & Yirmiya (1995) have published the only study exploring the implications of greater levels of self-awareness on the self-perceptions of high-functioning autistic children (n=18). These authors found that the majority of the children with autism viewed themselves as less competent than their non-autistic peers in social and physical, but not cognitive domains, as measured by the Perceived Competence Scale for Children (PCSC: Harter, 1982). Those children who viewed themselves more negatively, were also described by their parents as demonstrating higher levels of socially adaptive behaviour. This inverse relationship between parents' perceptions of their children's social abilities, and children's self-perceptions, demonstrated that children with better social abilities had greater awareness of their social

difficulties, and made more accurate self-appraisals. The children who viewed themselves more negatively (accurately), also demonstrated greater emotional understanding and had higher IQ scores, than those children who reported less accurate appraisals. The results support the hypothesis that accurate self-appraisals were possible because the children had applied their cognitive abilities to developing greater emotional and social understanding, which reduced the impairments inherent in their disorder. Capps et al. (1995) concluded that there was an urgent need for future research to explore, in greater detail, the psychological implications of awareness, particularly in relation to the link between negative self-evaluation and the risk of depression.

Research exploring comorbid mood disorders with high-functioning individuals with autistic spectrum disorders, have also highlighted an urgent need to identify and understand risk factors for depression within this high-functioning population with autistic spectrum disorders (see Lainhart, 1999). During the last five years, community and clinic-based research studies have reported high levels of comorbid mood disorder in high-functioning adults (Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998; Lainhart & Folstein, 1994), and children and adolescents with autism or AS (Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998; Ghaziuddin & Greden, 1998; Green, Gilchrist, Burton & Cox, 2000; Kim, Szatmari, Bryson, Streiner & Wilson, 2000). These studies have concluded that individuals with an autistic spectrum disorder are at greater risk for depression than the general (normally developing) population. It is, therefore, of increasing importance that correlates and risk factors for depression are identified and understood within this high-functioning autistic population.

One of the central hypotheses to emerge, regarding the aetiology and correlates of mood disorders, suggests that depression in AS reflects increased insight, and awareness of differences, among high-functioning individuals (Capps et al., 1995; Happe, 1994). A similar argument has been advanced within the learning disability literature to account for the higher incidence of depression amongst individuals who are mildly learning disabled, than amongst those who are moderately or severely learning disabled⁵ (Benson and Ivins, 1992; Reiss, 1985; Reiss & Rojahn, 1993). Apart from cognitive ability, we know little of the other psychosocial factors that mediate insight and potentially mediate depression. Capps et al. (1995) found striking evidence, which emphasised that, increased social and emotional understanding were direct correlates of greater accuracy and increasingly negative self-appraisals (insight), amongst high-functioning children and adolescents with autism. Given the strong relationship between negative self-appraisals and adolescent depression (Renouf & Harter, 1995; Lewinsohn, Gotlib & Seeley, 1997), within a normally developing adolescent group, it is apparent that future research should explore these correlates amongst a high-functioning population of children and adolescents with autism or AS. In doing this, the study would explore negative self-perception as one of a number of possible pathways to depression. Previous research has identified stressful life events as one factor that may contribute to the experience of depression for children with pervasive developmental disorders (Ghaziuddin, Alessi & Greden, 1995). Other links to depression may include downward social comparison, low self esteem and anger, however, the relationship with such variables, for individuals with an autistic spectrum disorder, has yet to be explored.

⁵ Of course, these results could simply reflect the insensitivity of current measures of depression, in detecting symptoms among individuals with limited language ability. Given the lack of research demonstrating the validity and/or reliability of standardised psychometric depression measures, caution will be exerted in both selecting and interpreting such measures.

This research, therefore, represents an exploratory study, investigating the implications of emotional understanding on self-perceptions and symptoms of depression, for a group of children and adolescents with Asperger syndrome. It is intended to increase understanding both of the implications of self-awareness and the psychosocial correlates of depression in this group of young people.

The Present Study

This study develops the research of Capps et al. (1995) by exploring the relationship between self-perceptions, emotional understanding and symptoms of depression in two groups of young people: high-functioning children and adolescents with autism and normally developing children and adolescents matched for age, gender and verbal ability.

The first objective was to compare the performance of the two groups on selected measures of emotional understanding (understanding of their own and others emotions), perceived self-competence, depression and socially adaptive behaviour. The study hypothesised that the AS group would perform significantly below the comparison group, on all measures. Thus, it was predicted that the AS group would perform less well on measures of emotional understanding and socially adaptive behaviour (parent report), and would report more negative self-perceptions and more symptoms of depression (parental and self-report), as compared to the comparison group. More detailed analyses comparing the groups performance on subscales of the Self-Perception Profile for Children (SPPC: Harter, 1985), will be carried out. It was hypothesised that the AS group would perceive themselves as less competent across all domains of the SPPC, except the scholastic competence domain.

The second objective replicated the work of Capps et al. (1995), in exploring the factors correlating with more negative self-appraisals or insight. Specifically, an inverse relationship was predicted between parental reports of socially adaptive behaviour and child reports of perceived competencies.

The third objective was to explore the factors correlating with self-report depressive symptoms among young people with AS. The study hypothesised that increased depressive symptom levels (parental and self-report) would be associated with lower overall perceptions of self-competence and better performance, on measures of emotional understanding and socially adaptive behaviour (parent report), within this group. These predictions suggest that children with AS who demonstrate improved emotional and social abilities will have greater insight into their difficulties and differences from others, and experience increased depressive symptoms.

METHOD

Study Design

The study followed a between group design. Comparisons were effected between two groups of young people matched for age, gender and verbal mental age (VMA), on standardised measures of perceived self-competence, emotional understanding and depression and on parental reports of social functioning and depression. All participants were children or adolescents, aged between 10 and 17, who were currently attending mainstream school and whose verbal abilities were within the normal range. Members of one group had received a diagnosis of Asperger syndrome, whilst the comparison group included normally developing children. Table 1 presents mean scores of individuals with and without AS, on demographic variables, and measures of verbal ability and symptoms characteristic of AS.

Participants

Participants with Asperger syndrome were recruited with the assistance of branches of the National Autistic Society located in the West of Scotland. The comparison group were selected with the co-operation of a local Scout Group, and matched with the AS group upon the respective bases of age, gender and VMA. Amongst the selection criteria used for the comparison group were included: no family history of autism/AS, no past or current record of needs, and no past or current psychiatric diagnoses. The difference between groups on these variables and on area social deprivation scores, as rated using the Carstairs Scores for Scottish Postcode Sectors (McLoone, 1991), was not significant ($p > .05$).

Table1: *Sample Characteristics: Mean (Standard Deviation) or Percentage by Child Group*

| Variable | Child Group | | <i>t</i> | U | <i>p</i> |
|-------------------|-------------------------------|----------------------------------|----------|------|----------|
| | Individuals with AS N = 15 | Individuals without AS N = 15 | | | |
| Child age (years) | 12.4 (2.2) | 12.1 (1.6) | -.52 | - | n.s. |
| BPVS-II score | 12.4 (32.6) | 12.5 (29.1) | .85 | - | n.s. |
| Sex (% boys) | 93.7 | 93.7 | - | - | n.s. |
| Carstairs score | 3.4 (1.2) | 3.1 (0.7) | - | 91.5 | n.s. |
| ASSQ score | 34.3 (9.3) | 0.5 (0.6) | - | .000 | <.001 |

Participants received information sheets and consent forms anonymously, distributed by the group leaders, and were invited to complete and return the consent forms (requesting that both child and parental consent be provided), if they wished to take part. Young people with AS were included in the study, if they had received, previously, a diagnosis of AS from a recognised clinician⁶ (e.g. Paediatrician, Clinical Psychologist, Psychiatrist) and also had

⁶ Currently, there are few valid diagnostic instruments specific to AS (see Howlin, 2000). There is also some debate surrounding who is eligible to make or confirm diagnoses of AS, according to current diagnostic criteria. It was thought,

scored above the cut off on parents reports on the Autism Spectrum Screening Questionnaire (ASSQ: Ehlers, Gillberg & Wing, 1999). The ASSQ is the *only* screening measure designed for school-age children, with AS or high-functioning autism for which detailed reliability and validity data are available. Each of the young people with AS registered scores above the cut-off of 19 (the optimal parent score for identifying autistic spectrum disorders), whilst the comparison group revealed scores of less than 2 on the ASSQ (see Table 1). The difference between the respective groups on this measure was highly significant ($p < .001$).

All participants were screened, using the British Picture Vocabulary Scale - II (BPVS-II: Dunn, Dunn & Whetton, 1997) to ascertain whether their receptive language abilities were within the normal range (see Table 1). There were no exclusions on this basis. The two groups, therefore, were demographically and cognitively similar, differing only with regard to measures of social difficulties, relating to the presentation of AS (see Table 1).

Procedures

Approval was obtained from the relevant local research ethics committees. Each participant, and his/her parents, gave informed verbal and written consent to all procedures. The interviews were conducted within the child's home. Participants were seen on one or two occasions so that fatigue could be kept to a minimum, by keeping each session to a maximum of 60 minutes.

Measures administered to children⁷

Emotional Understanding: Emotional understanding was assessed in two ways, using two

therefore, that the most reliable and valid means of diagnosis would be that conducted by a qualified clinician (e.g. Paediatrician, Psychiatrist, Clinical Child Psychologist). All participants had been diagnosed in this manner, prior to the study.

⁷ All measures, which are not routinely used in clinical practice, have been appended. See Appendix 3.3 for copies of the Children's Version of the Eyes Test (Baron-Cohen et al., 1998) and the SPPC (Harter, 1985).

measures: one assessing the child's understanding of the emotions of others, and the other assessing their ability to describe their own emotional experiences.

The first measure, the Children's Version of the Eyes Test (Eyes Test; Baron-Cohen et al., 1998) was selected as it is the only advanced test of theory of mind skills available, which has been developed for use with high-functioning children with autism or AS (see Appendix 3.3). The measure is adapted from the adult version of the Eyes Test (Baron-Cohen, Joliffe, Mortimore & Robertson, 1999). The main change involved the reduction in linguistic complexity of the target and foil words. The test was piloted with a sizeable number of children (n=53) and only those items which were reliably and correctly selected by over 50% of the sample children were retained (see Baron-Cohen et al., 1998 for details of test construction). The test has been found to differentiate adults (Baron-Cohen et al., 1997) and children (Baron-Cohen et al., 1998) with AS. Further to its development, it has been used in two other published studies (see Baron-Cohen, Wheelwright, Stone & Rutherford, 1997; Roeyers et al., 2001). It is a measure of the ability to interpret the emotions of others. The task involves inferring a person's mental state from information obtained in photographs of that person's eyes. Each of 28 pictures are shown and each required a forced choice response between four mental state terms printed around each picture.

The second measure, entitled Communication about own emotional experiences (OWNEE: Capps, Yirmiya & Sigman, 1992) comprises an interview, designed for use with children with autism or AS, which measures the ease with which a child can talk about his/her emotional experiences. It has been utilised in one further published study following its development (see Capps, Sigman & Yirmiya, 1995) and is one of the few available instruments to measure an

individuals understanding of their own emotions. For information on the development coding and scoring of the interview see Capps, Yirmiya & Sigman (1992). Each child is asked to describe a time when he/she felt each of four emotions (sadness, happiness, embarrassment and pride). The order in which different emotional experiences were elicited was rotated. In order to measure the difficulty of the task, latency of response was timed. The measure provides an overall score, representing the sum of the timed responses to each emotion. Responses can be explored further by comparing scores for the summed responses to simple (e.g. happy and sad) and complex (e.g. pride and embarrassment) emotions. Where the participant is unable to provide an answer, prompting, in the form of repetition, can be used whereby the examiner is able to offer a standard example of a time when he/she experienced the emotion.

Child-report depressive symptom measure: The Childrens Depression Scale – second research edition (CDS; Lang & Tisher, 1983) was selected because it has a parallel form for parents. It was also selected for its boxed response format, which added to the privacy afforded the responses, and reduced the verbal component of the task. The CDS has strong psychometric properties and has been found to have high internal consistency ranging from 0.92 to 0.94 (Bath & Middleton, 1985; Kazdin, 1987), good test-retest reliability, Tonkin and Hudson (1981) report a co-efficient of 0.74, and high convergent validity with the Child Depression Inventory (Kovacs, 1979), ranging from 0.92 to 0.94 (Kazdin, 1987). The CDS is a 66 item, self-rated scale. It uses a modified card-sort response format, with items individually listed on cards. The child is requested to sort the cards into five boxes labelled: very wrong, wrong, not sure, right, and very right. The CDS evaluates two broad factors, with 18 items comprising a ‘positive affective experience subscale’ and the remaining 48 items a ‘depression subscale’. The positive affect scale includes one subscale of eight items (pleasure and enjoyment), with

the remaining items described as miscellaneous. The depression subscale includes 5 subscales (affective response, self esteem, preoccupation with sickness and death, guilt, and loss of pleasure and enjoyment), along with 9 additional miscellaneous items. The depressive scale evaluates a range of symptom domains, including somatic, motivational, cognitive, affective and vegetative components of depression.

Self-perception measure: The Self-Perception Profile for Children (SPPC; Harter, 1985) is a revision of the Perceived Competence Scale for Children (PCSC; Harter, 1982), which has been used successfully with high-functioning children with autism (Capps et al., 1995). It is a 36 item self-report instrument measuring children's perceptions of self-competence and self-adequacy across six domains, including: scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct, and global self-worth (see Appendix 3.3). The profile of scores on the SPPC provides the fullest and most accurate picture of a child's self-concept, afforded by current psychometric measures, and demonstrates high internal consistency (.75 to .86), and good construct and discriminant validity (Harter, 1985). For each item, the respondent is asked as to which of two opposite statements is most like him/her (e.g. in games and sports, some kids usually watch instead of play BUT other kids usually play rather than watch), and then the degree to which the chosen statement best applies, measured on a two-point scale (really true for me OR sort of true for me). Scores are summed providing a total score and six subscale means, which will define a given child's profile. A similar boxed response format utilising a card-sort technique was used for the reasons outlined above (see child-report depressive symptom measure) and to maintain consistency in response formats across tasks.

Measures administered to parents

Social functioning: The Socialisation domain of the Vineland Adaptive Behaviour Scales - Survey Form (VABS; Sparrow, Balla & Cicchetti, 1984) was administered to one parent to supply a measure of adaptive social behaviour. The VABS consists of an interview, which provides standardised scores and age equivalents in four domains: communication, daily living skills, socialisation, and motor skills. Since the socialisation domain is that most applicable to this study, it was used to provide an objective measure of adaptive social behaviour, in the form of a standardised score. Low scores are indicative of less age-appropriate adaptive behaviour. The VABS has excellent test retest reliability ranging from 0.93 to 0.99 and the socialisation domain has excellent construct validity with factor loadings reaching significance at 0.75 (Cicchetti & Sparrow, 1981; Sparrow, Balla & Cicchetti, 1984). In addition, Vineland socialisation scores have been reported to have utility in clarifying the diagnosis of autism (Gillham, Carter, Volkmar & Sparrow, 2000).

Parent-report depressive symptom measure: The CDS – Adult Form (Tisher, 1995) consists of a separate set of statements, reworded for use with parents. Currently, there is no published data available regarding the use of self-report depressive symptom scales for children with autistic spectrum disorders, a scale with a parallel parent form was selected to provide some measure of reliability.

Statistical Approach

Power Calculation: The sample size was determined using a power calculation based on data from a similar study (Capps et al., 1995). The calculations indicated that, in order to demonstrate an effect size of 0.4, with a significance level of 0.05, and power held at 0.8, the

study would require 12 child participants, 6 in each group, for a comparison of group means using independent t-tests. Correlational analysis with similar settings would require 32 child participants, 16 in each group. The study, therefore, aimed for the larger of these figures and recruited 30 participants, 15 in each group.

Data Analysis: Data were analysed using SPSS version 9.0 for windows (SPSS inc., 1998). Descriptive statistics and frequency distributions were used to explore the data. One outlier was removed from the AS data set, which was a score on the OWNEE interview for complex emotions. Following from this, all data sets met the assumptions for parametric tests. Two statistical approaches were then employed. Firstly, between-group differences were investigated with independent t-tests. Secondly, associations between variables were calculated using Pearson correlation coefficients.

RESULTS

Coding

A reliability check was conducted on the OWNEE interview data. Two raters coded data from 7 participants (23% of the sample) and overall inter-rater agreement was achieved at a kappa value of 0.93 with consensus being reached on any disagreements. Coding revealed that six young people with AS could not recount a time when they had felt one of the four emotions. These responses were counted as missing data, and replaced with the mean group response to that emotion.

Between group differences

The results, shown in Table 2, demonstrated highly significant group differences in total scores on all measures, except the Children's Version of the Eyes Test. Specifically, the young people

Table 2: *Mean scores on all experimental measures for each group (SD in parentheses)*

| Measure | Child Group | | <i>t</i> | <i>df</i> | <i>p</i> |
|----------------------|---------------------|------------------------|----------|-----------|----------|
| | Individuals with AS | Individuals without AS | | | |
| | N = 15 | N = 15 | | | |
| Socialisation domain | 48.1 (15.1) | 112.8 (5.8) | -15.45 | 28 | <.001 |
| Eyes Test | 18.3 (14.8) | 19.7 (1.9) | -1.09 | 28 | n.s. |
| OWNEE (sec) | 82.1 (36.1) | 54.1 (35.7) | 2.10 | 27 | <.05 |
| SPPC | 83.9 (11.3) | 113.3 (14.7) | 6.14 | 28 | <.001 |
| CDS-child report | 148.2 (28.7) | 96.3 (17.7) | 5.94 | 28 | <.001 |
| CDS-parent report | 179.5 (25.9) | 94.0 (21.6) | 9.79 | 28 | <.001 |

with AS reported significantly greater symptoms of depression and significantly more negative self-perceptions. They were also significantly slower in their combined responses, dictated on the OWNEE interview. Further analyses revealed that the AS group were significantly slower in response to complex emotions ($t = 3.39$, $df = 27$, $p < .01$), but not in response to simple emotions ($t = 1.31$, $df = 28$, $p > .05$). Parents of children with AS reported observing increased symptoms of depression and less socially adaptive behaviour, as compared to the parents of normally developing children. The children and adolescents with AS received a mean score 4 standard deviations below the comparison group on the socialisation domain of the VABS. This underlines the fact that, although they are generally considered high-functioning, because of their cognitive and verbal abilities, young people with AS still experience chronic, daily social difficulties.

A comparison of scores shown on the subscales of the SPPC (shown in Table 3) revealed that the young people with AS viewed themselves as significantly less competent than young people without AS, in terms of social acceptance, athletic and behavioural competence, physical appearance and global self-worth. There was, however, no significant difference between either group's perception of their scholastic competence.

Table 3: *Mean scores on sub-scales of the Self-Perception Profile for Children (SD in parentheses)*

| SPPC Sub-scale | Child Group | | t | df | p |
|------------------------|-------------------------------|----------------------------------|-------|----|-------|
| | Individuals with AS N = 15 | Individuals without AS N = 15 | | | |
| Scholastic Competence | 15.9 (4.9) | 17.9 (2.8) | -1.37 | 28 | n.s. |
| Athletic Competence | 12.4 (3.3) | 18.1 (3.2) | -4.85 | 28 | <.001 |
| Physical Appearance | 15.5 (5.1) | 19.8 (3.2) | -2.79 | 28 | <.01 |
| Behavioural Competence | 14.9 (4.5) | 18.0 (3.1) | -2.23 | 28 | <.05 |
| Social Acceptance | 9.3 (3.7) | 19.5 (2.9) | -8.35 | 28 | <.001 |
| Global Self-Worth | 15.3 (4.1) | 20.3 (3.1) | -3.79 | 28 | <.001 |

Correlations with child reports of perceived self-competence

In the second set of analyses, the relationship between the child's reports of their self-competence (SPPC), and parental reports of socially adaptive behaviour (Socialisation domain) were computed. Similar to the findings of Capps et al., (1995), more negative perceptions of self-competence reported by the children with AS were associated with higher parental reports of socially adaptive behaviour, representing a significant inverse correlation ($r = -.48, p < .05$).

Correlations with child reports of depressive symptoms

In the third set of analyses, the relationship between young people's self-report depression scores, and measures of perceived self-competence and social and emotional understanding, were analysed for both groups (results are presented in Table 4). The AS group demonstrated a

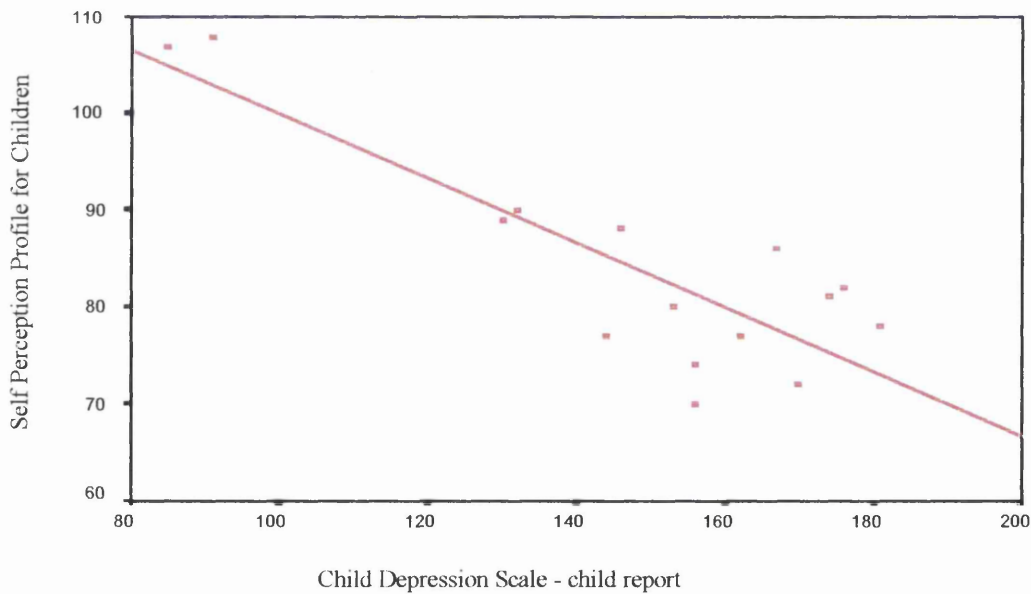
highly significant correlation between higher ratings of self-report depressive symptoms and more negative self-perceptions (see Figure 1), as did the normally developing group. The AS groups scores also revealed a strong association between higher ratings of self-report depressive symptoms and faster responses on the OWNEE interview.

Table 4: *Correlations with scores on the CDS -Child Report and all other measures for each group*

| Measures | Child Group | |
|----------------------|-------------------------------|----------------------------------|
| | Individuals with AS N = 15 | Individuals without AS N = 15 |
| Socialisation domain | .41 | .19 |
| Eyes Test | .003 | -.27 |
| OWNEE | -.48* | .34 |
| SPPC | -.85** | -.64** |
| CDS-parent report | .63** | .20 |

*p < .05
**p < .01

Figure 1: *The relationship between scores on the Child Depression Scale and the Self-Perception Profile for Children, for children with Asperger syndrome.*



Taken in combination, these results support the hypothesis that children and adolescents with AS, who report increased symptoms of depression, view themselves as less competent, and demonstrate greater ability to discuss their emotions, than those children with AS who report lower symptoms of depression. There was a trend towards significance for a positive correlation between child-report depressive symptoms and parents' reports of socially adaptive behaviour, suggesting that the children reporting higher depressive symptoms were those able to demonstrate greater socialisation skills. Parent reports on the CDS were positively associated with child reports, for young people with AS. However, this was not the case for the normally developing children, where parent and child reports of depressive symptoms showed no such agreement.

DISCUSSION

The results support the overall predictions of the study. They demonstrate a strong, empirical relationship between emotional understanding, insight and depressive symptoms, in a group of young people with Asperger syndrome (AS). They also provide information on the nature of these individuals' emotional understanding, self-perceptions, and experience of depressive symptoms, as compared to a normally developing peer group. These results will be discussed below in relation to autobiographical accounts and previous research findings. Finally, consideration will be given to the implications of these findings for clinical practice and future research.

Autobiographical writings (Happe, 1991; Kalen, 2000) and previous research (Capps et al., 1995) have each reported that high-functioning children with autism or AS can develop insight into their differences from others. This insight is thought to develop because these children apply their cognitive abilities to the improvement of their emotional understanding (Capps et

al., 1992; Roeyers, 2001) to levels higher than would be expected for individuals with an autistic spectrum disorder. The results of this study support such a thesis. The group of young people with AS demonstrated no significant difference in their performance on the Eyes Test, as compared to the comparison group. Furthermore, there were no group differences in latency of response to simple emotions revealed by the OWNEE interview, with the AS group demonstrating significant difficulties only on responses to complex emotions. Thus, the OWNEE interview distinguished between groups (in terms of responses to complex emotions), but the Eyes Test did not. The results are congruent with previous research (Capps et al., 1992) and demonstrate that the high-functioning children with AS can demonstrate improved emotional understanding, particularly on artificial tasks such as the Eyes Test (Roeyers, 2001).

These results also have implications for the validity of the Eyes Test as an instrument which can differentiate between children with and without AS. It is worth noting, however, that qualitatively, the two group's performance on the Eyes Test were not equivalent even though there was no statistically significant difference. This is highlighted by the difference in the variance of scores for each of the groups (see Table 2), with the AS group demonstrating much greater variability in performance. The AS group also completed the test more slowly and reported strategies which they were using in order to complete the task. It is difficult to say whether the Eyes Test is simply not a good instrument for identifying socio-cognitive deficits in high-functioning individuals with autistic spectrum disorders or whether it signifies more about difficulties with the validity or utility of the theory of mind to explain these individuals' social and emotional skill deficits. This issue is worthy of greater exploration and discussion than can be offered in the current paper (see Roeyers et al., 2001 for a recent discussion of this topic).

The majority of the young people with AS reported insight into their differences from others. Specifically, they displayed more negative self-evaluation on all domains of the SPPC, except the academic/scholastic domain. These results reflect accurate appraisals of equivalent cognitive abilities, offered by the children with AS, when comparing themselves to their normally developing peers. They also reflect high levels of awareness of social isolation and social difficulties. The children and adolescents with AS frequently reported a desire to have more friends, a wish that more people their age would like them, and an awareness that they were not very popular. These findings support autobiographical accounts (Kalen, 2000) of acute awareness of social exclusion from middle childhood. The results also replicate those documented by Capps et al. (1995).

As hypothesised by this study, young people with AS who provided more accurate self-appraisals were reported as displaying more socially adaptive behaviour, according to parental reports on the socialisation domain of the VABS, than those who were less accurate in their self-appraisal. Capps et al. (1995) have also demonstrated this inverse relationship between self-evaluation and parental evaluation of social competencies. This relationship appears to reflect the role of social understanding in promoting awareness of social differences, for children with AS.

The results described so far have found support for the relationship between improved abilities and insight within this population, an association originally reported by Capps et al. (1995). This study has also explored the relationship between insight and depressive symptoms for children and adolescents with AS. Firstly, results pertaining to the level of depressive

symptoms reported by the AS group will be described, followed by a discussion of their correlates.

As described earlier, recent studies have suggested that children and adolescents with AS are at greater risk of depression than the normally developing population (Green et al., 2000; Kim et al., 2000). Similarly, this study found that young people with AS endorsed significantly more symptoms of depression than a group of their peers without AS. In fact, 11 out of the 15 young people with Asperger syndrome reported depressive symptoms considered clinically significant for the normally developing population upon which the Child Depression Scale (CDS) has been standardised. These accounts were supported by powerful agreement between child and parent reports of the child's experience of depressive symptoms.

Based on personal accounts (Kalen, 2000) and previous research findings (Capps et al., 1995), this study predicted that elevated symptoms of depression would be related to more accurate (negative) perceptions of self-competence, and increased emotional understanding, and has found empirical support for this model. Specifically, those young people with AS who endorsed more symptoms of depression, demonstrated greater emotional understanding on a naturalistic task (OWNEE), and were reported by their parents as having improved social abilities. Emotional and social abilities were also related to more accurate self-appraisals, as described earlier. Hence, improved ability in being able to describe and share emotional material, and in more general social functioning, appears to be related to greater awareness of weaknesses and elevated reports of depressive symptoms.

In addition, the study found empirical evidence of the relationship between insight (reflected in negative perceptions of self-competence and self-adequacy reported on the SPPC), and depressive symptoms. The results support the hypothesis that negative self-appraisals play a central role in the experience of depressive symptoms, in young people with AS. The association between these factors is similar for normally developing adolescents (Lewinsohn et al., 1997; Renouf & Harter, 1995). This is an important finding, which highlights negative self-perceptions as one potential risk factor for depression, for children and adolescents with Asperger syndrome.

Summary

The results support the central predictions of the study, advocating the thesis that young people with AS who develop improved emotional and social abilities are more likely to acquire insight into their differences and experience increased symptoms of depression. In practical terms, the results suggest that insight for these young people is somewhat of a double-edged sword; on the one hand, it can promote improved social and emotional functioning, but on the other, can raise awareness of social difficulties, ostracism, and bullying, which can lead to symptoms of depression. It would seem that for these children with AS, knowing what they should be doing helps them to know what they are doing wrong. In addition, understanding that the way they do things is different, or below standard, is made all the more difficult because the social behaviours which they are trying to produce are innately difficult for them. Thus, this awareness may lead to frustration, hopelessness, and depressive symptoms.

Clinical implications

This research has demonstrated that the comparisons made by young people with Asperger syndrome, in terms of their relative strengths and weaknesses, may be central to their

experience of depressive symptoms. Clinical interventions which encourage both emotional and social skill development with children with an autistic spectrum disorder should be sensitive to this relationship between abilities, awareness and depressive symptoms. Helping children to generate coping strategies for managing this awareness may be equally, if not more important, than enhancing their social and emotional abilities. Interventions that assist both young people with AS, and their parents, in adopting realistic expectations of their abilities, and promoting a focus on strengths rather than weaknesses, may prove to be crucial in preventing depressive symptoms. Encouraging children with AS to focus on their relative strengths, by comparing their current abilities to their own previous functioning, to look for personal change and improvement, may also have some protective value. Similarly, comparing themselves to other children with autistic spectrum disorders may provide a more favourable and realistic comparison. For example, Kalen (2000), a high-functioning person with autism highlights her central coping strategy, as reminding herself that she is a "high-functioning autistic person, not a low-functioning person".

Future research directions and methodological issues

This study has demonstrated that the Child Depression Scale (CDS) has utility exploring self-report depressive symptoms with a population of young people with AS⁸, who often find it difficult to articulate their feelings. Future research, clarifying the validity and reliability of this measure, thereby producing normative data for children with autistic spectrum disorders, would have enormous clinical value, promoting early identification of depressive symptoms amongst high-functioning children with autistic spectrum disorders, presenting in mainstream clinical practice.

⁸ It would be of tremendous interest to explore the actual symptom profiles endorsed by the children with AS, however, this research question is beyond the scope of this paper.

Given the current lack of standardisation of the CDS, caution should be applied in interpreting the results of the AS group on this measure. However, whilst applying caution, due consideration should be given to the fact that young people in this group were declared as experiencing substantial symptoms of depression e.g. feelings of guilt, low mood, and low self-esteem. Thus, regardless of validity and reliability, the results of this study demonstrate that these children and adolescents were reported as having thoughts and feelings equivalent to a normally developing child's experience of severe depressive symptoms. In addition, the significant levels of agreement existing between child and parent reports of children's depressive symptoms in the AS group, provide some measure of reliability. Another methodological consideration concerns whether the high levels of clinically significant depressive symptoms reported by young people with AS, reflect a sampling bias. It is possible that the families who volunteered to participate in this study did so because they had concerns about their child's experience of depression.

CONCLUSIONS

The findings of the present study have important implications for clinical practice and it would be useful, therefore, for future research to replicate and extend them. A large-scale study, which sought to identify psychosocial factors differentiating between depressed and non-depressed sub-groups of high-functioning children and adolescents with an autistic spectrum disorder, would have immense clinical utility. Such a study might illuminate the protective and risk factors for depression, which is so often found within this population. However, prior to this, considerable exploratory research would be necessary to identify the relevant psychosocial variables, which should be included in such a study, as this research has highlighted only one

potential pathway to depressive symptoms, that involving heightened emotional understanding and negative self-perception. Research exploring the relationship between depressive symptoms and factors such as self esteem, social comparison, bullying, or anger, in young people with autistic spectrum disorders, may be important prospective steps for this research field.

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CHAPTER 5: CLINICAL RESEARCH CASE STUDY

Evaluating Narrative Therapy: A process and outcome study.

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Evaluating Narrative Therapy: A process and outcome study.

ABSTRACT

This study used a single-case research design to evaluate the effectiveness of Narrative Therapy (NT) in reducing the incidence of family conflict and problem behaviours with a family of a 9 year old boy. An ABC design was used to evaluate the effect of NT on target behaviours by comparing data from baseline (A), intervention (B) and follow-up (C) phases. The additive effect of NT techniques on these behaviours was analysed to test hypotheses regarding process issues and mechanisms of change. The family measured progress by counting the daily frequency of specific behaviours and weekly ratings of the subjective distress caused by these behaviours. Compared to baseline rates, the family showed improvement on all measures throughout the intervention stage, and gains were maintained at 1-month follow-up. Statistically significant improvements in problem behaviours occurred when "unique outcome" techniques were added to the intervention package, congruent with the assumptions of the NT model (White, 1989a). Implications of the study for future research are discussed.